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ABSTRACT

Representatives of several states met to identify basic elements of a tracking system designed to ensure that disabled and at-risk infants and their families receive continuous and appropriate services to improve health and developmental outcome. Discussants explored six clusters of questions concerning the following: realistic goals and rationale; criteria of client inclusion and discharge, including related ethical issues and range of risk categories; instruments and techniques needed for optimal tracking and linkage to services; awarding primary responsibility for the system and what effect this choice will have on the terminology used; and parent role. Experiences with tracking systems in Washington, Maryland, North Carolina, Utah, Iowa, and Texas contributed to the discussion. Materials from those six states comprise the appendices, which are the main content of the document, and include forms for recording data on children, program comparisons, program descriptions, and program guidelines and procedures. The Iowa High Risk Infant Followup Program is represented by a comprehensive medical form. North Carolina guidelines and procedures with sample forms are included virtually in their entirety as a reference for those interested in reviewing how one state-wide tracking system functions. (RH)

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KEEPING TRACK

Tracking systems for high risk infants and young children

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Keeping Track

Tracking systems for high risk infants and young children

NATIONAL CENTER FOR CLINICAL INFANT PROGRAMS

An exploration of issues based on a meeting sponsored by Project Zero to Three, A Special Project of Regional and National Significance supported by the Division of Maternal and Child Health, Grant NO. NCJ 113271-01-1, published by the National Center for Clinical Infant Programs.

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FOREWORD

"We've had the demonstration projects. Now how can we take what we've learned and get services to all disabled and at-risk children in our state who need them—starting from birth?"

"Our state's system of perinatal care is saving newborns who never would have survived a few years ago. But how can we make sure these babies get key follow-up care? How can the school system keep track of them and plan to meet their needs when they start school years from now?"

"How can we convince state legislators that early intervention is effective? What do we say when they ask what 'early intervention' means? What do we mean by 'effective'?"

Practitioners, parents and policymakers across the country who are concerned with the needs of disabled and at-risk infants, toddlers and their families are struggling with a set of questions like these, questions related to the broader issue of how we can establish permanent programs for this vulnerable population. There is growing commitment to serve handicapped children from birth to three. But this commitment must be reflected in support for services that remain in place year after year, services that families can count on. such an ongoing system must reflect accurately the need for services, ensure that agencies live up to delegated responsibilities, and include a mechanism for evaluating both the integrity of service programs and the quality of services offered in the light of new research in the field.

Because administrators at the state level are frequently in the lead in examining these issues, the Division of Maternal and Child Health began in 1983 to fund the National Center for Clinicial Infant Programs' Project Zero to Three, an initiative which brought together ten states (Maine, New Jersey, Maryland, North Carolina, Ohio, Iowa, Texas, Utah, Washington and Hawaii) well along in the process of building comprehensive service systems for disabled and at-risk children in the first three years of life. As representatives from these states voiced their concerns, plans were made to hold three meetings during the summer of 1984 to discuss:

1) Legislative mandates for serving disabled and at risk children from birth to three—What are the advantages, barriers, pitfalls and alternatives?

2) Systems for identifying and tracking high-risk (high priority) infants—What kinds of systems are most useful? How can improvements be made?

3) Program evaluation—What are the purposes of assessing the effectiveness of programs? How are the goals best accomplished?

"Keeping Track: Tracking Systems for High Risk Infants and Young Children" is a synthesis of a discussion which took place in Salt Lake City, Utah in the summer of 1984 and included facilitators James Blackman, M.D. of Iowa, Athleen B. Coyner, R.N., M.S., FAAN of Utah; representatives from the states of Iowa, Maryland, North Carolina, Texas, Utah and Washington; and staff from the Division of Maternal and Child Health and the National Center for Clinical Infant Programs. That interest in this topic is growing is reflected in the fact that two meetings on aspects of tracking were held in the summer of 1985, one under the sponsorship of Project START, a program of the Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, in conjunction with the National Association of State Directors of Special Education, Inc., and the Office of Special Education and Rehabilitative Services, and the other by NCCIP's Project Zero to Three. Reports of the issues raised in these meetings are in preparation.

"There Ought To Be A Law?: Ensuring State-wide Services for Disabled and At-Risk Infants and Toddlers" was published in the spring of 1985. The publication on program evaluation is in preparation.

Thanks for ongoing, invaluable support and assistance with this publication, as well as for every aspect of Project Zero to Three, go to Vince Hutchins, Merle McPherson and Camille Cook of the Division of Maternal and Child health, Bureau of Health Care Delivery and Assistance. Project Zero to Three committees in all ten states were not only instrumental in the framing of questions of most urgent concern to the field but also in providing cogent and perceptive comments and suggestions as "Keeping Track" was prepared.

SUMMARY

In a world in which parents of disabled or at-risk infants and young children had immediate, ongoing access to the best in information and in which services were known to be comprehensive and coordinated, there would be no need for special systems to follow the progress of "high-risk" children. But in the United States, midway through the 1980's, we are only beginning to understand the dimensions of the problems facing many vulnerable infants and their families. The range of services available in a community or state may reflect more what professionals and institutions know how to do, or have funding to do, than what children and families really need. And all too frequently program planners and service providers fail to form the alliances with parents which are essential to ongoing, integrated care for the disabled or at-risk child and his family.

A system is needed, therefore, to ensure that disabled and at-risk infants and their families receive continuous and appropriate services to improve health and developmental outcome.

Such a mechanism should

- begin prenatally
- focus on parents' and families' strengths and needs as well as the target child and
- ensure a smooth transition for child and family between services designed for a particular stage of development and between agencies.

This was the recommendation of representatives from Iowa, Maryland, North Carolina, Texas, Utah and Washington who met in Salt Lake City in July, 1984 under the auspices of Project Zero to Three, sponsored by the National Center for Clinical Infant Programs with the support of the U.S. Department of Health and Human Services' Division of Maternal and Child Health. Each of these states has established some form of system for the identification and tracking* of disabled and at-risk** infants and their families. Meeting participants discussed what can presently be said about the utility, the appropriate goals, and the methods of implementing such systems. Drawing on their own state level experiences and their review of a variety of tracking systems in settings around the country, James Blackman, M.D. of Iowa and Athleen B. Coyner, R.N., M.S., FAAN of Utah provided background for the group and facilitated the discussion of six critical questions. These questions were:

1. What are realistic goals for a tracking system? Why is such a system worth time and effort?
2. What are the criteria for including a child in a tracking system? What ethical issues are involved? If a system is not limited to traditional categories of biological and established risk, to what degree and by what means can it include children at environmental risk for impaired psychosocial development?
3. What are the criteria for discharging a child from a tracking system? If development seems to be proceeding normally, how long should an at-

*As used by meeting participants, the term "tracking" includes identification, monitoring and connection to an appropriate service provider. In the best of situations, a tracking system would also evaluate available services, and have a role in modifying them and reevaluating them. Tracking systems currently in operation may contain some or all of these elements.

**The term "at-risk" is used operationally by different agencies to describe very different infants, i.e. infants who because of conditions of birth or home environment may be expected to experience developmental problems; infants with identified conditions which are currently not impairing development but which may one day cause a problem; or infants who have not been identified by someone as having a problem but have not been recognized as disabled by a program or agency (those on screening or waiting lists, for example).

A number of tracking systems and service agencies are also using the following definitions of risk factors:

a. **Established risk,** which refers to diagnosed disorders where the condition is known to affect development (e.g., the congenital anomalies associated with Down's syndrome).

b. **Biological risk,** which refers to prenatal, perinatal, and neonatal events that may affect development (e.g., prematurity, low birth weight, abnormal neurological findings).

c. **Environmental risk,** which refers to high-risk environmental influences that may affect development (e.g., parent substance abuse, adolescent parenting, psychiatric stress).

risk child (including the environmentally at-risk) remain in the system?

4. What instruments and techniques are needed for optimal tracking and linkage to services?

5. What agency or group should have primary responsibility for a tracking system? How does the answer to this question affect the terminology used? Should responsibility shift as the child grows older? If so, how is such a transition best accomplished?

6. What is the role of the parent in a tracking system?

Without attempting definitive answers to all of these questions, the group did point out what could presently be agreed upon and identified issues which need further informed discussion.

Although the issue of funding for tracking systems was not among those originally listed for discussion by meeting participants, funding concerns were omnipresent. The amount of funding available will determine in basic ways the goals, structure, longevity and services offered by a tracking system. Funding levels control tracking systems by:

- *Determining the system's entry criteria*—the less money available, the more specific a system's criteria will have to be, and the smaller the likelihood of identifying many children with problems, especially those with a psychosocial component.
- *Determining the system's capacity for outreach activity*—with limited funding, a system may be restricted to a visible group of infants, such as NICU graduates. Older infants and toddlers and other vulnerable babies who might be identified outside a hospital context will be missed.
- *Affecting the quality and quantity of program staff*
- *Determining the longevity of a tracking system*—without reasonably long-term assurance of funding, tracking systems are unlikely to be able to meet either the data collection or service goals for which they were designed.

The source and amount of a tracking system's funding reflect its value to those responsible for health planning at the state level. Just as services for infants and toddlers must be established on a permanent basis if they are to go beyond models and demonstrations, so tracking systems must be seen as important enough to warrant allocation of state revenues and incorporation into the state health, human services and/or education plans if they are to endure and thrive.

1. What are realistic goals for a tracking system? Why is such a system worth time and effort?

A tracking system of periodic and sequential monitoring and understanding of a child and family should be viewed as one of many essential elements in achieving the larger goal of *fostering the health and development of disabled and at-risk children and their families.* A tracking system may have several sets of related goals.

First, the tracking system should attempt to make certain that *early identification leads to appropriate diagnosis and treatment, including early intervention services.* The system should not only identify handicapped and at-risk children and families but also their *needs;* it can thus be a process which allows a community or state to see how close its services come to meeting those needs and to plan appropriately.

A tracking system for high risk infants can be seen as a means of secondary prevention, in the public health sense. Early identification of problems in a population at risk affords the opportunity for intervention to prevent, reduce or ameliorate the severity of difficulties for the child and family.

Second, a tracking system can increase knowledge and lead to informed planning. It can *confirm, amend or expand current knowledge about the prevalence, etiology, incidence and outcome of a variety of conditions and disorders.* It can also document the numbers of children and families needing and using services, thereby providing data which can be used to plan for the allocation of financial and human resources over both the short and long term. If sensitive and appropriate measures of the outcome of services are available, these could also be included in the tracking system and become a valuable addition to the data base.

For example, the tracking system in Iowa found that approximately 20 percent of the biologically at-risk infants born in a given year require special educational and therapeutic services in the early years of life. Of the remaining 80 percent, one fourth manifest emerging learning difficulties which warrant specialized assistance at school entry. This information is helpful to the education system, which must prepare for these children to receive appropriate services at the earliest time.

Whether a tracking system is worth the time and effort expended by people and agencies who could be doing other things may be a question of perspective. Physicians in private practice may wonder whether doing the paperwork required by a tracking system makes sense if they fear that early intervention programs will result in the loss of their patients or are reluctant to "label" infants and young children with medical diagnostic classifications. Including primary care providers as well as tertiary center personnel in the planning of a tracking system is one way of being responsive to such concerns. Building fees for services rendered by primary care providers, especially pediatricians in private practice, into a tracking system and tying the system into the records already kept by practitioners may provide an immediate incentive to participation. Pro-

viding feedback to physicians and including them in the assessment and treatment of children and families may help them see the long-term worth of a tracking system.

In Washington, the state helps communities set up tracking systems which are run by local health departments. Comfortable with a local coordinating system and aware that such a system helps to keep children in physicians' care, pediatricians have responded to the tracking system with great enthusiasm.

The impact of a tracking system on families is also crucial to assessing its worth. Some parents may see such a system as a bureaucratic invention with little relation to ensuring the availability of appropriate services. They may feel money would be better spent publicizing and expanding services at the local level. A tracking system which "labels" children may alarm other parents. For many families, however, a tracking system provides reassurance and support for their own coping capacities.

Maryland's system, now operating on a demonstration basis, employs public health nurses to help parents use services in their community rather than having to transport children to central locations for service.

North Carolina and Washington have addressed the labeling issue in part by using the term "high priority" to replace "high risk." Such a term may be less intimidating to families the agencies seek to serve. Some professionals and planners are concerned, however, that so many groups of children deserve urgent attention that it is inappropriate to use the term "high priority" for a single population. They suggest that "high risk" be used to describe those children who need specialized monitoring systems to identify emerging needs which can be met by appropriate programs.

2. What are the criteria for including a child in a tracking system? If a system is not limited to traditional categories of biological and established risk, to what degree and by what means can it include children at environmental risk? What ethical issues are involved?

No consensus yet exists on the best predictors of later difficulties in development. Currently states are using a variety of criteria for including infants and children in tracking systems. Low birthweight, hospitalization in a neonatal intensive care unit or birth to an adolescent mother are frequently used indicators. Whatever criteria programs use should be legally authorized.

Iowa's medically-oriented system uses mostly biological criteria although an infant at environmental risk can be included at the nursery staff's discretion. Screenings with the Denver Developmental Screening Test (DDST) and neurological examinations are administered by pediatric nurse practitioners to eligible infants cared for in the state's 11 neonatal intensive care units. It is recognized that these screening procedures are not sufficiently sensitive or specific to detect low severity developmental dysfunction in the early years of life. Thus, tracking must continue into school age and the procedures must change to appropriately assess emerging developmental and behavioral skills. In Iowa, a new set of service needs were uncovered at age five among those children thought developmentally "clean" in the screenings conducted previously.

What is *not* yet known is the degree to which using broader or narrower definitions of a given criterion will sharpen the focus on the target group without leaving out many who should be included.

North Carolina has recently lowered the criterion for low birthweight from 2500 to 2000 grams. Both **North Carolina** and **Washington** have lowered the criterion for maternal age from 17—but North Carolina has lowered it to 14, Washington to 15.

An ongoing review of criteria which have had good predictive value could provide an important data base for refining current systems. This might be conducted across states, facilitated by the federal government.

While meeting participants disagreed about the wisdom of using such broad criteria as poverty or single parenthood for including a child in a tracking system, there was agreement that a broad system, including parental risk factors such as substance abuse, would be the ideal one. Such a broad system would permit a focus on children and needs *not* currently served—one of the main goals for a tracking system. Furthermore, systems which include both parental risk factors (including such psychosocial concerns identified at the time of childbirth) and infant criteria may be the most predictive of future developmental problems.

Moving beyond traditional categories to "doubly vulnerable" infants (at biological and environmental risk) and to situations in which the risk to a child seems primarily environmental requires possible involvement of other agencies, such as the mental health system, which may be following these children, and special sensitivity toward families as well. It seems to be the case at present that very few states consider environmental risk factors in tracking systems, probably because so few appropriate intervention services are available.

Risk factors like parental substance abuse or emotional health can be critical, but raise sensitive issues of privacy. Little stigma is attached to some non-biological risk factors which tend to result in speech and communication problems or mild retardation: these include age of parent; parity (4th child or greater); death, for any reason, of a previously liveborn child; or any fetal death. Since the notion of any kind of "parental assessment" can be extremely threatening, it

may not be feasible to perform such assessments, even though the information gained from the process may be considerably more predictive of the child's cognitive development than a mother's educational status alone.

Family privacy is not only an issue demanding sensitivity but also one of several important legal and ethical questions surrounding tracking systems. While any tracking system is voluntary, informed consent by parents should involve an understanding of the system's need to know particular kinds of information and the extent to which identification of problems is likely to result in the offer of services. Parents are often more willing to give data to a local health department than a state agency. If tracking system information is to be used for needs assessment and planning, data can be aggregated wherever possible and names omitted. Agencies should have carefully defined procedures for how the gathered data will be used and this information should be shared with parents.

Utah addresses confidentiality by taking the position that its tracking system is the guardian, not the owner, of information, with the responsibility for making sure that information is used for the child's benefit. In Utah, parents have tended to complain when agencies *fail* to share information with each other, confirming the sense of some meeting participants that "family privacy" may be misused as an excuse by agencies unwilling to share information for other reasons.

The issue of "labeling" a child through a tracking system is frequently raised. In one state not represented at the meeting, a child must be diagnosed as developmentally delayed to receive mandated services. If a pediatrician is reluctant to attach this "label," no identification, monitoring or services occur, and the child is not counted in the data base which is used to assess current and future needs for intervention services statewide.

Iowa has used the terms "deferred diagnosis" or "extended evaluation" to continue monitoring while avoiding a diagnosis of mental retardation.

One participant suggested a more neutral categorization for areas of tracking which would include impaired sensory input, central processing disorders, impaired motor output, family or environmental "feedback," physiological health and mental health. Other participants noted that terminology related to the *cause* of a problem, insofar as it is known, is important because it is tied so intimately to the type of intervention offered. Terminology which reflects a child's and family's *needs* may be particularly useful for linking families to services or helping planners assess needs statewide.

Whether to institute a tracking system when resources for intervention may not be available was a painful question for the group but not a difficult one. The group concluded that the agency administering a system should know, and should inform parents, if services are or are not available. In the absence of services, identification of children in need can stimulate the development of appropriate programs.

A parent in rural Washington told an interviewer: " How dare you not tell me if my baby has a problem! I'll beat the bushes to find services. Go ahead and screen!"

"Going ahead"—with full recognition of the need for ongoing review of the scientific basis for inclusion criteria and with respect for family integrity and privacy—seems to be the most promising direction for states interested in tracking systems for disabled and at-risk infants and young children.

3. What are the criteria for discharging a child from a tracking system?

A more positive way of phrasing this question might be to ask how we can assure adequate detection of problems and continuity of surveillance as children make the transition from systems tracking them from birth to age three (where original identification and linkage to services often comes from a medical facility or health agency) to educationally oriented systems. Tracking children until one year after they are dismissed from an intervention program was considered adequate by meeting participants to ensure linkage to services. However, a state's research and data base needs may be best served by tracking children and families, with their permission, well into the school years and, in some cases, until adulthood. Many at-risk children with conditions such as mental retardation, PKU or spina bifida may need services at particular periods, such as reaching reproductive age, or throughout their lifetimes. Meeting participants agreed that no arbitrary cut-off of tracking should occur at three years: "zero to three" programs must emphasize the importance of starting at birth and of a transition, rather than an end of services at three. During the first three years of life, moreover, dropping any high-risk child already in a tracking system seems unwise: we simply know too little about the etiology and onset of developmental problems.

Meeting participants suggested that since most medical problems decrease dramatically by 30 months, with remaining difficulties fairly visible, screening for older children in an educational, rather than a medical setting, would be appropriate as long as health evaluations and diagnostic routines are maintained. If schools take on the task of tracking high priority children for whatever period of time, they will need additional resources to do so.

4. What instruments and techniques are needed for optimal tracking and linkage to services?

"WANTED: Screening instruments. Inexpensive. Not so simple that children's problems will be missed, not so elaborate that expensive training or multiple/or highly experienced examiners are or will be necessary."

A want ad, rather than a recommendation for a specific screening instrument, may be a more accurate summary of the group's thinking, as a number of dilemmas were addressed. For example, although screening tests such as the Denver Developmental Screening Test are very widely used, they may be adequate for children under 30 months of age only when accompanied by a neurological examination. General screening tests of this sort have limitations in their usefulness after three years of age. They may miss many children who have more subtle disabilities of central processing. Thus, the instruments that are used must be appropriate for the age and developmental level of the child. If one is detecting mental retardation in a four-year-old, general screening tests may be adequate. If one is interested in problems related to memory, visual perception or language, more specific measures must be employed. The greater the degree of thoroughness with which screening is done, the fewer children (if resources remain constant) can be included in a tracking and screening program. However, meeting participants suggested that it is cost-efficient and productive to have highly trained professionals screen at-risk children because they are able to supplement the DDST or other tools by assessing the quality of a child's performance and using their observational skills to analyze more parameters of development.

Recognizing the need to encourage the trial of promising but as yet invalidated new instruments in model and demonstration programs and, above all, to encourage ongoing sharing of information about clinical diagnostic tools, the group made several suggestions for:

- A literature review of available instruments leading to preparation of a guide to diagnostic tools which measure specific items
- An advisory group made up of individuals who have had experience in tracking systems and who could advise states considering, or in the process of establishing, such system
- Use of EPSDT or State Block Grant funds for training personnel to perform assessments and for implementation of a tracking system. Home visits by public health nurses to children identified as needing services might be a specific focus for support.

5. What agency or group should have primary responsibility for a tracking system? How does the answer to this question affect the terminology used? Should responsibility shift as the child grows older?

The allocation of primary responsibility for tracking of disabled and at-risk children in the first three years of life will vary from state to state depending on the language of relevant legislation or on the available sources of commitment, expertise and interest. Whichever agency takes the lead at various stages, consultation with other agencies concerned with infants, toddlers and their families is crucial.

Given that hospitals are a natural point of entry to the tracking system, that most community referrals come from primary care providers, and that public health nurses may already be involved with the neediest families, health providing agencies may be the most logical candidates. If another agency takes the lead, the health emphasis should nonetheless be a major one, at least until age three. If a transition then occurs, some overlap, for purposes of continuity, seems advisable.

In Utah, several innovative approaches have been employed for early identification of children and following their transition into the educational system. For example, information from the birth certificate, supplied by physician and parent, is used to identify hearing impaired infants in the first months of life. This has led to a project which will use a similar process to identify a high risk population of up to 20% of the total population. This high risk population would need to include at least 70% of those children who eventually would be identified as handicapped in order for the process to be considered successful.

Iowa's High Risk Infant Tracking System serves as a conduit for infants and young children with developmental needs to enter the educational system mandated to serve children from birth onward. Once a child has passed from Iowa's High Risk Infant Follow-up, Iowa's Special Education System takes the lead responsibility and the child is dropped from the High Risk Tracking System.

A broad coordinating committee including representatives from health, education, social services, mental health and mental retardation agencies might be an effective means of establishing a tracking system. Consultation and consensus on the population to be served and the criteria for inclusion are, of course, essential. If, for example, the tracking system plans to address parents' psychosocial and emotional status, involvement of the state mental health agency will be needed.

Meeting participants noted that administrative tools such as interagency agreements, memoranda of understanding and common computer registry forms are as vital to the success of a tracking program as clinical instruments used to measure aspects of a child's development. Each agency or service provider (such as a neonatal intensive care unit or a speech, language and hearing agency) may have its own system of definitions and classification, but certain terms for common usage

must be agreed upon by all those involved in a tracking system. Whatever data collection communities undertake, creating and maintaining a data base at the *state* level is important for the needs assessment and planning functions of a tracking system.

Texas is presently addressing the problem of common definitions. In a state-wide meeting that included 36 representatives from numerous public and private agencies; planners, administrators, practitioners, and educators; and a regional representative of DMCH, the Texas Zero To Three Committee explored ways to link data bases, barriers to doing so, and the advantages to having a centralized tracking system. The group concluded that the following four reasons for tracking systems are to the advantage of the population at large, and of all agencies.

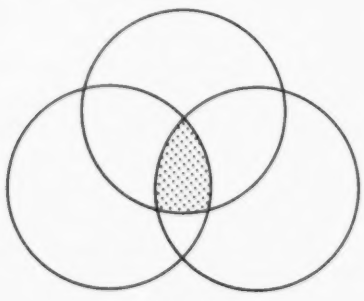
(1) to verify the services provided and to provide epidemiological data for this population;
(2) to provide data for the justification of new funds;
(3) to provide data for effective planning for the special education needs of children;
(4) to provide the population from which to draw representative research samples to answer questions of cost-effectiveness and educational effectiveness.

Perhaps these will be useful as motivators to find common definitions.

In Iowa, placement in a diagnostic category is sometimes deferred by the education system because the labels developed for school aged children are not definitive enough for the very young child. The child who is determined to be in need of services is then programmed for within the "extended evaluation" full service option while further diagnostic follow-up is being conducted.

The reality of funding requirements may necessitate that an agency use one label for entry to a service program and a different label that reflects the child's actual needs. Labels may change as the child moves through the education system, which depends on P.L. 94-142 categories of disability. Since all agencies have equally strong requirements and need for flexibility, it is not surprising that lack of common definitions can present a major barrier.

Utah conceptualizes its system graphically, with the circles representing the information collected by local health departments, private providers and specialized agencies and the shaded area representing the information sent to the central registry.



Given broad agency involvement and consensus on the features of a tracking system, it may be possible or desirable for a neutral agency, such as a university, and developmental disabilities council or consumer group to operate a tracking system. Such an organization might leave actual assessment to the health, human services or education department and function rather as the manager of the tracking system and as advocate for the family and child. Legal mechanisms to ensure confidentiality would be an issue in such a system.

6. What is the role of the parents in the tracking system?

As highly concerned and knowledgeable individuals who play a critical role in advocating for needed services and in managing their child's use of care, parents have the right and responsibility to be involved in the design and implementation of a tracking system. That no parents were among the representatives at the Salt Lake City meeting was felt as a real omission.

Meeting participants agreed, as indicated in section 2, that informed consent by parents to inclusion in a tracking system should signify an active choice rather than passive acquiescence. Tracking systems should encourage parents to see themselves as owners of information about their child, with the right to obtain *all* information entered into or generated by any data collection system, and with the authority to release data to themselves for review or to any specific agency which might be serving their child.

In **Utah's** planned system, parents would agree to participate in a Central Registry as they requested services. Parents could choose not to participate or to withdraw.

Recognizing that undertaking responsibility for advocacy may be neither appropriate nor possible for some parents and that others are not concerned with more general questions of identification and follow-up, a tracking system might nevertheless serve a useful function by advising parents of advocacy opportunities and teaching them advocacy skills.

One model for managing a tracking system might include a consumer panel comprised of a coalition of parent groups. There is a need, however, to guard against self-interest dominating such a system.

CONCLUSION

In our large and diverse nation, part of a complex and less than perfect world, state tracking systems of periodic and sequential surveillance of disabled and at-risk children may be an important step toward ensuring continuous and appropriate services to improve the health and developmental outcome of vulnerable infants and toddlers.

As the Utah meeting made clear, even states with more than a decade of experience in planning, implementing and refining follow-up systems do not yet have answers to questions as basic as the best criteria for inclusion in a tracking system or even the most appropriate instruments to use in screening and monitoring infant and young children. States now considering or planning a tracking system will not be followers along well-trodden paths as much as co-explorers of largely uncharted territory. Learning by doing, exploring the benefits and disadvantages of a variety of criteria, instruments, and administrative strategies, will continue to be a major means of accumulating knowledge—about vulnerable children and their families, about the challenges they face in development, about the most effective means of helping them reach their full potential, and ultimately, about preventing disability.

Understanding and respect, trust and communication are critical to every aspect of successful tracking systems. It is important to remember that tracking systems tend to come into existence precisely because consumers, professionals and institutions so often feel unable to trust each other's data, capacity to respond to need, or terminology. Tracking systems need parents who are knowledgeable owners and reporters of information about their children; they need professionals and organizations committed to overcoming obstacles to understanding; they need state and federal governments willing to devote time and resources to a full exploration of etiology, prevention and remediation of biological and environmental risks to healthy development. As these grow, we may come closer to our goals.

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*Van Dyck, Peter C., White, Frederick I. and Kaminsky, Christia. *Creating an Information Base for Program Collaboration* (Part of the *Workbook Series for Providing Services to Children with Handicaps and Their Families*, prepared by Georgetown University Child Development Center for the Division of Maternal and Child Health), May, 1984.

*Portions included in Appendix.

APPENDICES

Project Zero to Three participants in Iowa, Maryland, North Carolina, Texas, Utah and Washington who came to the Salt Lake City meeting are actively engaged in developing, testing, evaluating, refining and expanding tracking systems in their states and in communicating their experiences—and their questions—to other groups in Project Zero to Three and across the country who share their commitment to ensuring access to appropriate services for disabled and at-risk infants, toddlers and their families.

As staff of the National Center for Clinical Infant Programs attempted to include materials in this publication illustrating tracking projects or systems in all six states, we realized that we ourselves were trying to track a rapidly moving target. No sooner would one state send us a newly revised form or brochure than another would withdraw a previous submission because *it* was about to be improved. Readers are therefore encouraged to use the materials which follow in the appendices to stimulate their own thinking. For up-to-date information, they are advised to contact the meeting participants listed at the conclusion of this publication and Project Zero to Three, The National Center for Clinical Infant Programs.

North Carolina guidelines and procedures are included virtually in their entirety as a reference for those interested in reviewing how one state-wide tracking system functions, from concept to format.

Iowa

THE IOWA HIGH-RISK INFANT FOLLOW-UP PROGRAM

The purpose of the Iowa High-Risk Infant Follow-Up Program, begun in 1978, is to identify the developmental and special health needs of infants at developmental risk, to initiate referrals to appropriate agencies if definitive evaluation and remediation are required, to offer support to parents, and to facilitate the family's use of community resources. The program has six components.

1. Implementing a statewide process for identifying and tracking infants and children whose births were associated with specific factors that put them at risk for later manifesting developmental disorders;
2. Determining reliable, valid, and cost-effective methods for identifying such children and their developmental needs as early as possible;
3. Helping the primary health care provider coordinate the service referral process for children and families with identified needs;
4. Determining the training needs and providing educational programs for personnel involved in identifying and caring for such children;
5. Collecting, storing, analyzing, and interpreting the data emanating from the program; and
6. Disseminating the results of these findings to other states or regional comprehensive child health service systems.

The program has been a natural outgrowth of earlier efforts to improve perinatal health care in Iowa. Serving primarily as a screening and referral program for children born with biologic and related risk factors, the program, now in its sixth year, is reaching 80 percent of eligible children, based on the established risk criteria. The program has been gathering important information on the outcomes of children with various risk factors through its long-term follow-up efforts; a total of 2,600 referrals based on developmental and health concerns have been made during its first five years of effort.

Pediatric nurse practitioners complete this form on all enrollees from Iowa City, Des Moines and Cedar Rapids.

IOWA HIGH RISK INFANT FOLLOWUP PROGRAM
Form 1
Rev. 4/84

BASELINE DATA

GENERAL CODING INSTRUCTIONS:

Every item whose code is to be entered in a box must be coded on every form. NO BLANK BOXES - except in coding infant's hospital number.

Any coding areas designated by lines relate to the preceding box coded item and may be left blank only if that preceding item code meets the specified criteria for skipping.

Code for unknown (missing data): Unless otherwise specified, code a [9] in each blank for that item.

Code for "not applicable": Unless otherwise specified, code an [8] in each blank for that item.

Computation of hours: [0-60 minutes] = 1 hour; [61-120 minutes] = 2 hours; [121-180 minutes] = 3 hours; etc.

Computation of days: [0-24 hours] = 1 day; [25-48 hours] = 2 days; [49-72 hours] = 3 days, etc.

Coding for trimesters: First △ = First 3 months of pregnancy
Second △ = Months 4, 5, 6
Third △ = Month 7 until delivery

Columns

Form Number [1] (1)
Card Number [01] (2- 3)

[A] IDENTIFYING DATA:

Followup Number: [ ][ ][ ][ ][ ] (5- 9)

(First digit is hospital enrolling child in followup program. If any NICU care is given at University of Iowa Hospitals, the child is assigned a U of I number.)
1=University of Iowa Hospitals, Iowa City
2=St. Luke's Methodist, Cedar Rapids
3=Iowa Methodist Medical Center, Des Moines
4=St. Luke's Regional Medical Center, Sioux City
5=Ottumwa General Hospital, Ottumwa
6=Mercy Hospital, Mason City
7=St. Luke's Hospital, Davenport
8=St. Francis Hospital, Waterloo

Enrollment Type: [1] (11)

Child's Name: [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ], [ ][ ][ ][ ][ ][ ][ ][ ] (13-31)
last first

Parent's (or guardian's) Name: _____
last first

Address: _____
street city

_____ _____
county state zip

Telephone: ( ) -
area number

Birthdate: (mo, day, yr) ☐☐☐☐☐☐ (33-38)

Sex: 1=male 2=female 3=undifferentiated ☐ (40)

Child's number at enrolling hospital: ☐☐☐☐☐☐☐☐☐☐ (42-51)
(Begin number in column 42-code actual (42)
number-do not fill with 0)

Transferred: 1=No, inborn 2=Yes ☐ (53)
(If "no" - go to Col. 64)

Referral hospital: (Use State Department of Health codes. (Appendix A) Out of state hospital code 99-9) __ __ - __ (55-57)
county hosp

Level of transport to enrolling hospital: __ (59)

1=Transport by Level I hospital, birth enroute, other arrangement by LMD, private auto
2=Transport by Level II hospital
3=Ground transport by Level III hospital
4=U of I air care
5=Other air transport

Age at arrival at enrolling hospital: (days) __ __ (61-62)

Enrollment criteria met: Code 1=No 2=Yes

Birthweight < 1500 grams: ☐ (64)

RDS: (documented diagnosis in chart, differentiated from other signs of respiratory distress, must have had assisted ventilation and/or CPAP ≥ 2 hours) ☐ (66)

Clinical diagnosis of CNS infection: ☐ (68)

Asphyxia neonatorum: (5 minute apgar ≤ 6) ☐ (70)

Hypoglycemia: (two consecutive blood glucose levels ≤ 40 mgm %) ☐ (72)

Seizures: (documented in physicians progress notes with concurrence of staff neonatologist (Level III) or attending pediatrician (Level II) ☐ (74)

Hypotonia: (documented in chart at time of discharge) ☐ (76)

Ventilatory assistance ≥ two hours: ☐ (78)

Other reason (primary) for enrollment: (Code "no" unless none of eight criteria listed above are met.) ☐ (80)

1=No
2=Hyperbilirubinemia
3=SGA
4=Sepsis
5=IVH
6=Sib meets criteria
7=Psychosocial concerns
8=Other

Form Number 1 (1)
Card Number 02 (2- 3)
Repeat cols. 5-9 from Card 1 (5- 9)

Current status in High Risk Program: ☐☐ (11-12)
01=Active
02=Lost to followup - no screening exams
03=Direct referral to local program (e.g., AEA) - no screening exams
04=Direct referral to University Hospital School - no screening exams

Followup site (use enrollment center codes) ☐☐ (14-15)

B SOCIOECONOMIC DATA: (Information valid at time of infant's birth)

Mother's age: (years) ☐☐ (31-32)

Father's age: (years) ☐☐ (34-35)

Mother's race: 1=Caucasian 2=Caucasian, Spanish surname ☐ (37)
3=Black 4=Am. Indian 5=Oriental 6=S.E. Asian 7=Other

Father's race: 1=Caucasian 2=Caucasian, Spanish surname ☐ (39)
3=Black 4=Am. Indian 5=Oriental 6=S.E. Asian 7=Other

Mother's marital status: 1=Single 2=Engaged (includes cohabitation) ☐ (41)
3=Married 4=Separated 5=Divorced 6=Widowed

Mother's domicile: (1980 census) 1=Rural, Farm (< 2,499 population) ☐ (43)
2=Rural, Non-farm (< 2,499 population) 3=Town (2,500-14,999)
4=City (15,000-49,999) 5=Urban (≥ 50,000)

Codes for education type and level:

Type: 1=Regular
2=Resource (e.g., "mainstreamed", consistent LD classes but also participates in regular classrooms)
3=Self contained (separate classrooms within regular facility and/or institutionalization)

Level: Code the highest elementary or secondary grade completed plus one year for each year of college completed:
(26-28 hours undergraduate level; 15-18 hours graduate level)
Guidelines: 01-12=elementary through high school
12=GED
13=Vocational, trade school completion
14=Associate of Arts Degree
15=RN, diploma
16=RN, BS
16=BS, BA
18=MA
20=Medical, dental, legal, veterinarian degree

Mother's education type: ☐ (45)

Mother's education level: ☐☐ (47-48)

Father's education type: ☐ (50)

Father's education level: ☐☐ (52-53)

Infant's county of residence at time of enrollment: ☐☐ (55-56)
(Appendix B)

Form Number 1 (1)
Card Number 03 (2- 3)
Repeat cols. 5-9 from Card 1 (5- 9)

C MEDICAL HISTORY

Antepartum History

Gravida: (Number of pregnancies regardless of outcome - include this birth) ☐☐ (11-12)

Parity: (Number of deliveries - include stillborns and this birth. Multiple births constitute a single delivery.) ☐☐ (14-15)

Stillborn deliveries: (≥ 20 wks. GA; If none, code 0) ☐ (17)

Abortions: (< 20 wks. GA; If none - code 0) ☐ (19)

Neonatal deaths: (death at ≤ 28 days; If none - code 0) ☐ (21)

Infant deaths: (death at > 28 days and ≤ 1 yr.; If none - code 0) ☐ (23)

Previous multiple deliveries: (If none - code 0) ☐ (25)

Current Pregnancy

Weight gain: (kilograms - greatest gain prior to delivery) ☐☐.☐ (27-29)

Prenatal care begun: ☐ (31)

1 = first △ 2 = second △ 3 = third △ 4 = no prenatal care

Prenatal physician: (physician giving more than 50% of care) ☐ (33)

1 = Family practitioner
2 = Obstetrician, Level I
3 = Obstetrician, Level II
4 = U of I OB Department (includes care given at U of I staffed OB clinics in Davenport, Muscatine and Waterloo)

Any of the following medications taken during pregnancy: 1=No 2=Yes ☐ (35)
(If "No" go to Col. 50)

Type medications: Code 1=No 2=Yes

Steroids _ (36)

Antinausea _ (37)

Antibiotics _ (38)

Street drugs _ (39)

Aspirin _ (40)

Other antipyretics _ (41)

Anticonvulsants _ (42)

Antihypertensives (includes diuretics) _ (43)

Decongestants/Antihistamines _ (44)

Smoking during pregnancy: 1=No 2=Yes ☐ (50)
(If "No" - go to Col. 54)

Number of packs smoked per day: 1= < one 2=one to two
3=more than two _ (51)

Smoking terminated during pregnancy: 1=No 2=Yes _ (52)

Alcohol regularly consumed (continuance of pre-pregnancy pattern) during pregnancy: 1=No 2=Yes ☐ (54)
(If "No" - go to Col. 57)

Regular consumption of alcohol stopped during pregnancy: _ (55)

1=first △ 2=second △ 3=third △ 4=not stopped

Amniocentesis: (If first △ - code second △) 1=No 2=second ☐ (57)
3=third 4=second and third △ 's
(If "no" - go to Col. 62)

Primary reason for amniocentesis: _ (58)

1=Fetal maturity (usually after 25 weeks gestation)
2=Genetic dx (usually between 16-20 weeks)
3=Rh problem (24-40 weeks)
4=Fetal maturity and genetic dx
5=Fetal maturity and Rh
6=Genetic dx and Rh
7=Other

LS: (closest to delivery) 1=mature (L:S ratio ≥ 2.1-including infant of diabetic mother) 2=not mature, L:S ratio < 2.1 __ (59)

SHAKE: 1=mature 2=not mature __ (60)

Abdominal ultrasound during pregnancy: 1=No 2=Yes, primary reason specified below 3=Yes, other reason
(If Code 1 or Code 3 - go to Col. 65) ☐ (62)

__ (63)

1=Fetal maturity
2=Fetal abnormality
3=Multiple gestation
4=Routine

Was this mother referred to a Level II or Level III perinatal center for delivery following the identification of obstetrical risk factors
1=No 2=Yes ☐ (65)

Were any of the following maternal diseases present: (during this pregnancy unless otherwise specified) 1=No 2=Yes
(If "No" - go to Card 4, Col. 11) ☐ (67)

Disease present: Code 1=No 2=Yes

Hypertension: (> 140 systolic or > 90 diastolic) __ (68)

Pre-eclampsia: (edema, proteinuria and hypertension without seizures __ (69)

Eclampsia: (convulsions related to pre-eclampsia in last trimester until ≤ 48 hours post delivery) __ (70)

Rh sensitive: (must have diagnosis in chart, not just Rh- with Rh+ infant) __ (71)

Heart disease: __ (72)

Gestational diabetes: (diabetic only when pregnant) __ (73)

Diabetic: (onset prior to conception, permanent condition)
1=No 2=Yes, not insulin dependent 3=Yes, insulin dependent __ (74)

Urinary tract infection: (either positive culture or symptomatic treatment without culture. Code earliest △ dx.)
1=No 2=first △ 3=second △ 4=third △ 5=Yes, △ unknown __ (75)

Thyroid disease: 1=No 2=past history and treatment
3=Yes, treated during this pregnancy __ (76)

Vaginal bleeding: (requiring medical attention, excludes that occurring just prior to labor and delivery or placenta previa) __ (77)

Form Number 1 (1)
Card Number 04 (2- 3)
Repeat cols. 5-9 from Card 1 (5- 9)

Were any of the following viral illnesses present during pregnancy:
1=No 2=Yes
(If "No" - go to Col. 18) ☐ (11)

Code: 1=No 2=Yes

"Common cold": __ (12)

Herpes: (oral) __ (13)

Herpes: (genital) __ (14)

Chicken pox: __ (15)

Influenza: __ (16)

ICD codes for other significant maternal disease: (specify)
(If none - go to Col. 30)

_____ ___.__ (19-22)

_____ ___.__ (24-28)

LABOR AND DELIVERY

Weeks gestation of completed pregnancy by dates: [ ][ ] (30-31)

Labor: 1=none 2=spontaneous (may include later use of pitocin to stimulate labor) 3=induced, primary reason listed 4=induced, other reason
(If Code 1, 2, or 4 - go to Col. 36) [ ] (33)

_ (34)

1=Post datism
2=Failure to progress
3=Elective
4=PROM > 24 hours
5=Diabetes
6=Rh
7=Pre-eclampsia/eclampsia

Duration of rupture of membranes: If 0-12 hours, code 00.5; 13-24 hours, code 01.0; if ≥ 25 hours, code days as outlined in general coding instructions. [ ][ ].[ ] (36-38)

Fluid: 1=clear 2=meconium stained 3=foul smelling 4=meconium and foul smell 5=bloody [ ] (40)

Amount of fluid: 1=normal 2=oligohydramnios 3=polyhydramnios [ ] (42)

Prolonged labor: (primipara first stage > 18 hours; or second stage > 2 hours; or multipara first stage > 12 hours; or second stage > 1 hour. Applies to labor prior to C-section also) 1=No 2=Yes [ ] (44)

Were any of the following drugs used to delay labor (any time during pregnancy): 1=No 2=alcohol 3=ritodrine/terbutalin 4=vasodilan 5=alconol and vasodilan [ ] (46)

Type delivery: 1=vaginal, vertex (any rotation) 2=vaginal, breech 3=vaginal, other (includes face, arm, shoulder presentation) 4=C-section, indications listed 5=C-section, other indications only
(If Code 1, 2, 3, or 5 - go to Col. 59) [ ] (48)

Indication for C-section: Code 1=No 2=Yes

CPD: _ (49)

Repeat: _ (50)

Fetal distress: (documented in chart; includes placenta previa and abruption) _ (51)

Diabetes: _ (52)

Rh: _ (53)

Pre-eclampsia/eclampsia: _ (54)

Breech: _ (55)

Failure to progress: _ (56)

Amnionitis: _ (57)

Forceps used: (code highest type used successfully) 1=None 2=attempted, none successful 3=low, includes Pipers on head 4=mid, includes forceps rotation 5=high [ ] (59)

Anesthesia: 1=No 2=Yes, type listed 3=Yes, other type
(If Code 1 or 3 - go to Col. 69) [ ] (61)

Type anesthesia: Code 1=No 2=Yes

Local: __ (62)

Epidural: __ (63)

Paracervical: __ (64)

Pudendal: __ (65)

Saddle/Spinal: __ (66)

General: __ (67)

Were any of the following medications given during labor prior to delivery: 1=No 2=Yes [ ] (69)
(If "No" - go to Card 5, Col. 11)

Medications administered: Code 1=No 2=Yes

Demerol __ (70)

Nisentil __ (71)

$MgSO_4$ __ (72)

Pitocin __ (73)

Valium __ (74)

Vistaril __ (75)

Deladumone __ (76)

Seconal __ (77)

Nubain __ (78)

Form Number [1] (1)
Card Number [05] (2- 3)
Repeat cols. 5-9 from Card 1 (5- 9)

Fetal heart rate monitoring: 1=none 2=external 3=internal 4=both [ ] (11)
(If "none" or "external" - go to Col. 16)

Lowest scalp pH recorded: __ . __ __ (12-14)

[D] NEONATAL

Resuscitation at birth: (treatment within the first hour of life) 1=No 2=Yes [ ] (16)
(If "No" - go to Col. 25)

Type resuscitation: Code 1=No 2=Yes

O_2 mask or in oxyhood - no positive pressure used: __ (17)

O_2 bag and mask, positive pressure used: __ (18)

Intubation - ETT with bagging, assume with O_2: __ (19)

Narcan: __ (20)

Volume expander: __ (21)

$NaHCO_3$/THAM: __ (22)

Other drugs: __ (23)

Birthweight: (use nursery weight - grams) [ ][ ][ ][ ] (25-28)

Length: (within first 3 days of life - cm) [ ][ ].[ ] (30-32)

OFC: (within first 24 hours of life - cm) [ ][ ].[ ] (34-36)

Gestational age by exam: (Ballard - weeks) ☐☐ (38-39)

(To code: if infant asphyxiated use Ballard after 6-12 hours of age if available.
If range ≥ 2 weeks - code mean
If 2 consecutive weeks - code earlier GA
If more than 2 weeks discrepancy between physician's and nurses assessment (Level II), discuss with infant's pediatrician.
If infant transferred to U of I < 5 days of age - use U of I gestational exam.
If < 26 - code 26 - use this also in computing adjusted age for screening exams.)

Size compared to GA: (Colorado growth chart, GA by exam) ☐ (41)
1=average 2=large 3=small

One minute Apgar: ☐☐ (43-44)

Five minute Apgar: ☐☐ (46-47)

Multiple Birth: 1=No 2=Yes, twin 3=Yes, triplet
4=Yes, quadruple ☐ (49)
(If "No" - go to Col. 52)

Birth order of this infant: __ (50)

Hypothermia within first hour of life: (rectally < 96.5° F or 35.8° C; axillary < 95.5° F or 35.3° C) 1=No 2=Yes ☐ (52)

Hypoglycemia: 1=No 2=suspected, two chemstix ≤ 40 (or dextrostix < 45) or one chemstix ≤ 40 (or dextrostix ≤ 45) with treatment 3=Yes, at least one true glucose ≤ 40 mg% ☐ (54)

Hypocalcemia: (CA++ < 7.0 mg/100 ml or ionized value ≤ 2.5) 1=No 2=Yes, not treated 3=Yes, treated ☐ (56)

Polycythemia - within first 24 hours of life: (Central hematocrit ≥ 65 and/or peripheral hematocrit ≥ 70) 1=No 2=Yes ☐ (58)
(If "No" - go to Col. 67)

Highest central hematocrit: __ __ . __ (59-61)

Highest peripheral hematocrit: __ __ . __ (62-64)

Treatment: 1=none 2=partial exchange 3=other __ (65)

Hypotension: (within first 2 hours of life - values according to Kitterman, et al, Appendix C) 1=No 2=Yes, systolic or mean value below 95% confidence level for weight ☐ (67)

Apnea: 1=No 2=Yes, documented in physicians' progress notes or hospital's apnea sheet, treatment indicated below 3=Yes, documented as in No. 2, other treatment ☐ (69)
(If 1 or 3 - go to Card 6, Col. 11)

Type of treatment: 1=No 2=Yes

Stimulation/observation: __ (70)

CPAP: __ (71)

Respirator: __ (72)

Theophylline/caffeine: __ (73)

Form Number 1 (1)
Card Number 06 (2- 3)
Repeat cols. 5-9 from Card 1 (5- 9)

Sepsis: 1=No 2=suspected, ≥ 7 days antibiotics, cultures negative 3=Yes, proven by positive blood and/or CSF culture ☐ (11)
(If "No" or "suspected" - go to Col. 22)

Number of proven episodes: __ (12)

Were any of the following organisms identified by blood and/or CSF culture: 1=No 2=Yes, blood culture 3=Yes, CSF culture 4=Yes, both cultures

Beta hemolytic strep: __ (13)

E Coli: __ (14)

Klebsiella: __ (15)

Streptococcus pneumonia: __ (16)

Pseudomonas: __ (17)

Staphylococcus aureus: __ (18)

Urine culture positive during hospitalization: 1=No 2=Yes ☐ (22)

Respiratory distress: (infant required oxygen therapy ≥ 2 hrs.) ☐ (24)
1=No 2=Yes
(If "No" - go to Col. 42)

Reasons for oxygen therapy: Code 1=No 2=Suspected 3=Yes, physicians's diagnosis

Apnea: __ (25)

Pulmonary hypoplasia: __ (26)

Pneumothorax/pneumomediastinum: __ (27)

CNS depression: __ (28)

Transient tachypnea of the newborn/wet lung: __ (29)

Congenital heart disease: __ (30)

Aspirate pneumonia: (meconium) __ (31)

Aspirate pneumonia: (amniotic fluid or other) __ (32)

Pneumonia: __ (33)

Asphyxia: __ (34)

PFC: __ (35)

Congenital malformation: __ (36)

Etiology unknown: __ (37)

RDS: __ (38)

X-ray consistent with RDS: 1=No 2=Inconclusive 3=Yes __ (39)

Surgery: (Code yes only if none of above reasons present) __ (40)

Complications occurring chronologically after a documented cause for/and treatment of respiratory distress: (If Respiratory distress item coded "No" - code this item "8", not applicable) 1=No 2-Yes ☐ (42)
(If "No" or not applicable - go to Col. 52)

Type complication: Code 1=No 2=Yes (unless otherwise specified)

Atelectasis: __ (43)

Interstitial air/emphysema: __ (44)

Pneumothorax: __ (45)

Pneumomediastinum: __ (46)

Pneumopericardium: __ (47)

Pulmonary hemorrhage: __ (48)

Bronchopulmonary dysplasia/Chronic lung disease: __ (49)

RLF: (Code greatest degree) 1=No 2=Grade I 3=Grade II 4=Grade III 5=Grade IV 6=Grade V __ (50)

Respiratory therapy: (Any respiratory assistance including the use of oxygen occurring anytime during hospitalization. If O_2 for surgery only and concentration is unknown, code duration in hours, code concentration unknown.) 1=No 2=Yes ☐ (52)
(If "No" - go to Card 7, Col. 26)

Initial episode: (Continuous O_2 needs from start of O_2 to first discontinuation of O_2 for 24 or more hours)

Initial form of respiratory support: 1=hood 2=CPAP nasal 3=CPAP mask 4=CPAP ET 5=ventilator __ (53)

Age oxygen started: (hours) ___ (54-56)

CPAP

Most aggressive CPAP measure used: 1=none 2=nasal only (includes NP) 3=mask 4=ET __ (57)

Age CPAP started: (actual age in days, even if only for weaning) ___ (58-60)

Duration of CPAP alone: (hours, include weaning time) ____ (61-64)

CPAP→ventilator: 1=No 2=Yes __ (65)

Ventilator

Age ventilator started: (hours) ___ (67-69)

Time on ventilator: (hours) ____ (70-73)

Maximum CPAP and/or PEEP: __ (74-75)

Maximum peak pressure: __ (76-77)

Maximum rate: ___ (78-80)

Form Number 1 (1)
Card Number 07 (2- 3)
Repeat cols. 5-9 from Card 1 (5- 9)

Oxygen

Time in oxygen: (hours) ____ (10-14)

Time in $FiO_2 \geq 0.40$: (hours) ____ (15-18)

Time in $FiO_2 \geq 0.70$: (hours) ____ (19-22)

Maximum FiO_2: __.__ (23-25)

Subsequent respiratory therapy: (Total of all additional episodes after discontinuation of O_2 for at least 24 hours)

Time in O_2: (Hours; If zero hours - go to Col. 45) ☐☐☐☐ (26-29)

Time in $FiO_2 \geq 0.40$: (hours) ____ (30-33)

Time in $FiO_2 \geq 0.70$: (hours) ___ (34-36)

Maximum FiO_2: __.__ (37-39)

Time on ventilator: (hours) ____ (40-43)

pH Values: (Any time during hospitalization)

Highest recorded: ☐.☐☐ (45-47)

Lowest recorded: ☐.☐☐ (48-50)

Cardiac: (Were any of the following conditions documented or suspected during the infant's hospitalization) 1=No 2=Yes ☐ (52)
(If "No" - go to Col. 63)

PDA: 1=No 2=Suspected, clinical evidence such as LA/AO ratio increase, pulses full, increased heart size by x-ray, no treatment 3=Suspected, clinical evidence present and treated (digitalis and/or fluid restriction) 4=Yes, documented by surgery and/or catheterization _ (53)

Age at diagnosis: (days) __ (54-55)

Age at surgical ligation: __ (56-57)

CHF: 1=No 2=Suspected 3=Yes _ (58)

Congenital heart disease: 1=No 2=Suspected 3=Yes _ (59)

PFC: 1=No 2=Suspected 3=Yes _ (60)

Myocardial ischemia: 1=No 2=Suspected 3=Yes _ (61)

Seizures: 1=No 2=Suspected, observation by other personnel, not documented by physician 3=Yes, documented by physician ☐ (63)
(If "no" - go to Col. 67)

Age at onset of seizures: (days) (suspected or documented) __ (64-65)

Head ultrasound: 1=No 2=Yes, results normal 3=Yes, results abnormal ☐ (67)

Head CT: 1=No 2=Yes, results normal 3=Yes, results abnormal ☐ (69)
(If ultrasound and CT are both coded 1 or 2 - go to Card 8, Col. 18)

Type abnormal results: Code 1=No 2=Yes

Consistent with IVH: _ (70)

Enlarged ventricles: _ (71)

Porencephalic cysts: _ (72)

Consistent with ICH other than IVH: (e.g., subdural, subarachnoid, intraparenchymal thalamic, venous thrombosis and hemorrhage) _ (73)

Other abnormal results: _ (74)

Most severe grade of IVH documented: _ (75)

1=Grade I, Subependymal hemorrhage
2=Grade II, IVH with normal sized ventricles
3=Grade III, IVH with enlarged ventricles
4=Grade IV, IVH with extension into the cortex

Form Number 1 (1)
Card Number 08 (2- 3)
Repeat cols. 5-9 from Card 1 (5- 9)

Treatment of abnormality: Code 1=No 2=Yes

Observation: _ (11)

Serial L.P's: _ (12)

Ventricular tap: _ (13)

Shunt: _ (14)

Other - specify: _____ __ (15)

_____

_____

Did abnormality on ultrasound and/or CT revert to normal prior to discharge: Code 1=No 2=Unclear 3=Partial resolution 4=Yes __ (16)

Necrotizing enterocolitis: 1=No 2=Suspected, treated or clinically compatible but not proven 3=Yes, documented by surgery or x-ray evidence of intramural air ☐ (18)
(If "No" - go to Col. 23)

Age of onset of signs: (days) __ __ (19-20)

Surgery performed: 1=No 2=Yes __ (21)

Transfusions:

Blood or blood product transfusions: 1=No 2=Yes ☐ (23)

Complete exchange transfusion/s: 1=No 2=Yes ☐ (25)
(If "No" - go to Col. 37)

Age at first exchange: (days) __ __ (26-27)

Number of exchange transfusions: __ __ (28-29)

Indication for exchange transfusion: 1=No 2=Yes

Hyperbilirubinemia: __ (30)

RDS: __ (31)

Sepsis: __ (32)

Metabolic problems: __ (33)

DIC: __ (34)

Other: __ (35)

Bilirubin drawn: 1=No 2=Yes ☐ (37)
(If "No" - go to Col. 54)

Maximum total bilirubin: (mg%) __ __ . __ (38-40)

Maximum direct bilirubin: (mg%) __ __ . __ (41-43)

Maximum indirect bilirubin: (mg%) __ __ . __ (44-46)

Age at highest total bilirubin: (days) __ __ (47-48)

Positive direct Coomb's: 1=No 2=Yes __ (49)

ABO setup: 1=No 2=Yes __ (50)

Rh setup: 1=No 2=Yes __ (51)

Phototherapy: 1=No 2=Yes __ (52)

Catheters: 1=No 2=Yes ☐ (54)
(If "No" - go to Col. 64)

Umbilical artery line: 1=No 2=Yes, above diaphragm (T10) 3=Yes, above bifurcation (L5) 4=Yes, both locations 5=Yes, location unknown __ (55)

Duration of UAL: (days; if none code 00) __ __ (56-57)

Used for CVN administration: 1=No 2=Yes __ (58)

Umbilical venous line: 1=No 2=Yes __ (59)

Duration of UVL: (days; if none - code 00) __ __ (60-61)

Arterial line other than UAL: 1=No 2=Yes ___ (62)

Hyperalimentation (CVN or PVN): 1=No 2=Yes 3=Intralipids only ☐ (64)
(If "No" - go to Col. 72)

Duration of CVN: (days; if none code 00) ___ (65-66)

Duration of PVN: (days; if none code 00) ___ (67-68)

Duration of intralipids: (days; if none code 00) ___ (69-70)

Antibiotic therapy during total hospitalization: 1=No 2=Yes ☐ (72)
(If "no" - go to Card 9, Col. 14)

Were any of the following antibiotics administered: 1=No 2=Yes

Ampicillin ___ (73)

Gentamicin ___ (74)

Kanamycin ___ (75)

Cephalosporins ___ (76)

Methicillin ___ (77)

Penicillin/Penicillin G ___ (78)

Ticarcillin/Carbenicillin ___ (79)

Chloramphenicol ___ (80)

Form Number 1 (1)
Card Number 09 (2- 3)
Repeat cols. 5-9 from Card 1 (5- 9)

Total duration of aminoglycosides-e.g., Kanamycin, Gentamicin: (days) ___ (11-12)

Were any of the following medications administered to infant during total hospitalization: 1=No 2=Yes ☐ (14)
(If "no" - go to Col. 54)

Medications: 1=No 2=Yes

Aldactone ___ (15)

Aminophylline/Theophylline ___ (16)

Apresoline ___ (17)

Atropine ___ (18)

Caffeine ___ (19)

Calcium ___ (20)

Chloral-Hydrate ___ (21)

Curare ___ (22)

Digoxin or other glycoside ___ (23)

Dilantin ___ (24)

Dopamine ___ (25)

Epinephrine/Adrenalin ___ (26)

Ethacrynic Acid ___ (27)

Heparin ___ (28)

Indomethacin ___ (29)

Insulin	__	(30)
Isuprel/Isoproterenol	__	(31)
Kayexalate	__	(32)
Lasix	__	(33)
Magnesium	__	(34)
Morphine or other narcotics	__	(35)
$NaHCO_3$	__	(36)
Narcan	__	(37)
Norepinephrine	__	(38)
Paregoric	__	(39)
Pavulon	__	(40)
Plasmanate/Albumin	__	(41)
Phenobarbital	__	(42)
Prostaglandins/Prostaglandin E	__	(43)
Steroids	__	(44)
THAM	__	(45)
Thyroxin	__	(46)
Tolazoline/Priscoline	__	(47)
Valium	__	(48)
Vitamin D	__	(49)
Vitamin E	__	(50)

Additional documented diagnoses not elsewhere coded: 1=No 2=Yes [ ] (54)
(If "No" - go to Col. 61)

Diagnosis: 1=No 2=Yes

TEF:	__	(55)
DIC:	__	(56)
Gastroschisis/omphalocele:	__	(57)
Viral illness (documented rise in viral titers):	__	(58)
Fetal alcohol syndrome:	__	(59)

ICD codes for other significant neonatal disorders not recorded on this form: 1=No 2=Yes [ ] (61)
(If "no" - go to Card 10, Col. 11)

_____	___.__	(62-66)
_____	___.__	(67-71)
_____	___.__	(72-76)

Form Number [1] (1)
Card Number [10] (2- 3)
Repeat cols. 5-9 from Card 1 (5- 9)

[E] DISCHARGE DATA: Code all discharge data on basis of infant's oldest chronological age upon discharge from U of I Hosp/C.R. St. Luke's or IMMC [ ] (11)

Discharged to:

1=Home
2=Foster home
3=Level I hospital
4=Level II hospital
5=Other tertiary center - out of state
6=Other out-of-state hospital

Weight at discharge: (gm - within 3 days of discharge) ☐☐☐☐ (13-16)

Length at discharge: (cm - within 3 days of discharge) ☐☐.☐ (18-20)

OFC at discharge: (cm - within 3 days of discharge) ☐☐.☐ (22-24)

Total number of days hospitalized from birth: ☐☐☐ (26-28)

Discharged on any of the following life support/monitor systems: 1=No 2=Yes
(If "No" - go to Col. 45) ☐ (30)

Oxygen: 1=No 2=Yes, without ventilatory support 3=Yes, with ventilatory support ☐ (31)

Apnea Monitor: 1=No 2=Yes ☐ (32)

Data Base Type: 1=Single enrollment center data 2=Combined data from two High Risk enrollment centers ☐ (45)

This baseline data form is completed for those infants enrolled through Level II centers where time devoted to the program by PNPs is limited.

IOWA HIGH RISK INFANT FOLLOWUP PROGRAM
FORM 4
Rev. 4/84

BASELINE DATA

GENERAL CODING INSTRUCTIONS:

Every item whose code is to be entered in a box must be coded on every form. NO BLANK BOXES.

Any coding areas designated by lines relate to the preceding box coded item and may be left blank only if that preceding item code meets the specified criteria for skipping.

Code for unknown (missing data): Unless otherwise specified, code a [9] in each blank for that item.

Code for "not applicable": Unless otherwise specified, code an [8] in each blank for that item.

Columns

Form Number [4] (1)

Card Number [01] (2- 3)

[A] IDENTIFYING DATA:

Followup Number: ☐☐☐☐☐☐ (5- 9)

(First digit is hospital enrolling child in followup program. If any NICU care is given at University of Iowa Hospitals, the child is assigned a U of I number.)

1=University of Iowa Hospitals, Iowa City
2=St. Luke's Methodist, Cedar Rapids
3=Iowa Methodist Medical Center, Des Moines
4=St. Luke's Regional Medical Center, Sioux City
5=Ottumwa General Hospital, Ottumwa
6=Mercy Hospital, Mason City
7=St. Luke's Hospital, Davenport
8=St. Francis Hospital, Waterloo

Enrollment Type: ☐ (11)

Child's Name: ☐☐☐☐☐☐☐☐☐☐, ☐☐☐☐☐☐☐☐ (13-31)
last first

Parent's (or Guardian's) Name: _____
last first

Address: _____
street city

_____
county state zip

Telephone: ( ) -
area number

Local Physician _____

_____

Birthdate: (mo, day, yr) ☐☐☐☐☐☐ (33-38)

Sex: 1=male 2=female 3=undifferentiated ☐ (40)

Child's number at enrolling hospital: ☐☐☐☐☐☐☐☐☐☐ (42-51)
(Begin number in column 42) (42)

Transferred: 1=No, inborn 2=Yes ☐ (53)

Enrollment criteria met: Code 1=No 2=Yes

Birthweight < 1500 grams: ☐ (55)

RDS: (documented diagnosis in chart, differentiated from other signs of respiratory distress, must have had assisted ventilation and/or CPAP ≥ 2 hours) ☐ (57)

Clinical diagnosis of CNS infection: ☐ (59)

Asphyxia neonatorum: (5 minute apgar ≤ 6) ☐ (61)

Hypoglycemia: (two consecutive blood glucose levels ≤ 40 mgm%) ☐ (63)

Seizures: (documented in physicians' progress notes with concurrence of staff neonatologist (Level III) or attending pediatrician (Level II) ☐ (65)

Hypotonia: (documented in chart at time of discharge) ☐ (67)

Ventilatory assistance ≥ two hours: ☐ (69)

Other reason (primary) for enrollment: (code "no" unless none of eight criteria listed above are met) ☐ (71)

1=No
2=Hyperbilirubinemia
3=SGA
4=Sepsis
5=IVH
6=Sib meets criteria
7=Psychosocial concerns
8=Other

Current status in High Risk Program: ☐☐ (73-74)

01=Active
02=Lost to followup - no screening exams
03=Direct referral to local program (e.g., AEA) - no screening exams
04=Direct referral to University Hospital School - no screening exams

Infant's county of residence at time of enrollment: ☐☐ (76-77)
(Appendix A)

Was this mother transferred to a regional perinatal center prior to delivery (following the identification of risk factors): ☐ (79)
1=No 2=Yes

Form Number 4 (1)

Card Number 02 (2- 3)

Repeat cols. 5-9 from Card 1 (5- 9)

[B] NEONATAL

Resuscitation at birth: (treatment within the first hour of life) ☐ (11)
1=No 2=Yes
(If "No" - go to Col. 20)

Type resuscitation: Code 1=No 2=Yes

O_2 mask or in oxyhood - no positive pressure used: ___ (12)

O_2 bag and mask, positive pressure used: ___ (13)

Intubation - ETT with bagging, assume with O_2: ___ (14)

Narcan: ___ (15)

Volume expander: ___ (16)

$NaHCO_3$/THAM: ___ (17)

Other drugs: ___ (18)

Birthweight: (use nursery weight - grams) ☐☐☐☐ (20-23)

Length: (within first 3 days of life - cm) ☐☐.☐ (25-27)

OFC: (within first 24 hours of life - cm) ☐☐.☐ (29-31)

Gestational age by exam: (Ballard - weeks) ☐☐ (33-34)

(To code: If infant asphyxiated use Ballard after 6-12 hours of age if available
If range ≥ 2 weeks - code mean
If 2 consecutive weeks - code earlier GA
If more than 2 weeks discrepancy between physician's and nurse's assessment (Level II), discuss with infant's pediatrician
If infant transferred to U of I < 5 days of age - use U of I gestational exam
If < 26 - code 26 - use this also in computing adjusted age for screening exams.)

Size compared to GA: (Colorado growth chart, GA by exam) ☐ (36)
1=Average 2=Large 3=Small

One minute Apgar: ☐☐ (38-39)

Five minute Apgar: ☐☐ (41-42)

Sepsis: 1=No 2=Suspected, ≥ 7 days antibiotics, cultures negative ☐ (44)
3=Yes, proven by positive blood and/or CSF culture

Necrotizing enterocolitis: 1=No 2=Suspected, treated or clinically compatible ☐ (46)
but not proven 3=Yes, documented by surgery or x-ray evidence of intramural air

Apnea: 1=No 2=Yes, documented in physicians' progress notes or hospital's apnea ☐ (48)
sheet
(If "No" - go to Col. 53)

Type of treatment: 1=No 2=Yes

Stimulation/observation: ___ (49)

CPAP: ___ (50)

Respirator: ___ (51)

Theophylline/caffeine: ___ (52)

PDA: 1=No 2=Suspected, clinical evidence such as LA/AO ratio increase, pulses ☐ (53)
full, increased heart size by x-ray no treatment 3=Suspected, clinical evidence present and treated (digitalis and/or fluid restriction) 4=Yes, documented by surgery and/or catheterization

Head ultrasound: 1=No 2=Yes, results normal 3=Yes, results abnormal ☐ (55)

Head CT: 1=No 2=Yes, results normal 3=Yes, results abnormal ☐ (57)
(If ultrasound and CT are both coded 1 or 2 - go to Col. 65)

Type abnormal results: Code 1=No 2=Yes

Consistent with IVH ___ (58)

Enlarged ventricles: ___ (59)

Porencephalic cysts: ___ (60)

Consistent with ICH other than IVH: (e.g., subdural, subarachnoid, intraparenchymal thalamic, venous thrombosis and hemorrhage) ___ (61)

Other abnormal results: ___ (62)

Respiratory therapy: (Any ventilatory assistance including the use of oxygen occurring anytime during hospitalization. If O_2 for surgery only and concentration is unknown, code duration in hours, code concentration unknown) 1=No 2=Yes ☐ (65)
(If "No" - go to Col. 68)

Ventilator: 1=No 2=Yes ___ (66)

CPAP: 1=No 2=Yes ___ (67)

Bronchopulmonary dysplasia/Chronic lung disease: 1=No 2=Yes ☐ (68)

Bilirubin drawn: 1=No 2=Yes ☐ (70)
(If "NO" - go to Card 3, Col. 11)

Maximum total bilirubin: (mg%) ___ ___ . ___ (71-73)

Phototherapy: 1=No 2=Yes ___ (74)

Form Number 4 (1)

Card Number 03 (2- 3)
Repeat cols. 5-9 from Card 1 (5- 9)

ICD codes for other significant neonatal disorders not recorded on this form: 1=No 2=Yes ☐ (11)
(If "No" - go to Col. 31)

_____ ___ ___ ___ . ___ ___ (13-17)

_____ ___ ___ ___ . ___ ___ (19-23)

_____ ___ ___ ___ . ___ ___ (25-29)

ICI DISCHARGE DATA:

Weight at discharge: (gm - within 3 days of discharge) ☐☐☐☐ (31-34)

Length at discharge: (cm - within 3 days of discharge) ☐☐.☐ (36-38)

OFC at discharge: (cm - within 3 days of discharge) ☐☐.☐ (40-42)

Total number of days hospitalized from birth: ☐☐☐ (44-46)

DISCHARGE MEDS _____

RLF CHECK _____

HEARING CHECK _____

NEONATAL SCREEN _____

This form is used to record the results of the program's physical and developmental screening.

IOWA HIGH RISK INFANT FOLLOWUP PROGRAM
SCREENING EXAMINATION

NAME: _____ HOSPITAL NUMBER _____

(1- 3) 2 _ 1 Form Number Exam Number Card Number P.N.P. _____

(4- 8) _ _ _ _ _ Followup Number

(9-14) _ _ _ _ _ _ Date of Exam (mon. day yr.) Age Calculation

Today's date: _____

(15-20) _ _ _ _ _ _ Birthdate (mon. day yr.) Birthdate: _____

Chron. Age: _____

(21-23) _ _ _ _ Chronological Age (mon. wk.)

(24-25) _ _ Estimated Gestational Age (weeks)

(26-28) _ _ _ Adjusted Age (mon. wk.)

EVALUATION SUMMARY

PHYSICAL EXAMINATION
1= No abnormality detected
2= Positive findings present requiring attention and/or referral
3= Positive findings previously recorded, status quo
4= Positive findings requiring parental monitor with possible physician consultation
5= Physician consultation at screening exam
6= Physician exam deferred at this time to be completed by an associated program
7= Combination of any of above. Specify: _____

BODY MEASUREMENTS

(29-31) _ _ _ Weight (kg)

(32-33) _ _ Weight %tile (For %tiles, code 99 if > 95; code 01 if < 05)

(34-37) _ _ _ _ Length (cm)

(38-39) _ _ Length %tile

(40-42) _ _ _ OFC (cm)

(43-44) _ _ OFC %tile

SYSTEM

(45) _ HEENT: _____

(46) _ Pulmonary: _____

(47) _ Cardiac: _____

(48) _ Abdomen: _____

(49) _ Genitalia: _____

(50) _ Extremity: _____

(51) _ Other: _____

NEUROLOGICAL EXAMINATION 1= no 2= yes 3= suspected

(52) _ Visual deficit: _____

(53) _ Hearing deficit: _____

(54) _ Hypotonia: _____

(55) _ Hypertonia: _____

(56) _ Nonprogressive neuromuscular disorder: _____

(57) _ Other: _____

(58) _ DEVELOPMENTAL SCREENING: 1. DDST 2. Hosp. School Screening Exam 3. not done 4. Other (specify) _____

(59) _ Results: 1. normal 2. abnormal 3. questionable 4. untestable

(60) _ SIGNIFICANT INTERCURRENT HISTORY: 1.no 2.yes (also code below) 3.unknown

(61) _ Major illnesses: _____

(62) _ Rehospitalization: _____

(63) _ Psychosocial: _____

(64) _ Surgery: _____

(65) _ Other: _____

REFERRALS

(66) _ LMD: 1.no 2.yes, acute problem 3.yes, maintenance REASON _____

Other specialty referrals and/or involved agencies: 1=no 2=yes 3=already followed 4=refused by parents 5=refused by LMD

(67) _ Neonatal Followup Clinic: _____

(68) _ Subspecialty Clinic: _____

(69) _ Social Service: _____

(70) _ Public Health: _____

(71) _ Iowa Comm. Blind: _____

(72) _ AEA: for speech and/or hearing screening _____

(73) _ Hospital School: _____

(74) _ Infant Educational Program: _____

(75) _ Preschool: _____

(76) _ Other: _____

(77) _ High risk screening recheck: _____

(78) _ AEA for developmental evaluation as a result of "failed" screening examination/s _____

(79-80) _ _ Examination site _____

PHYSICAL EXAMINATION	N	A	Comments
General appearance			
Skin (color, texture, scars, bruises, nevi, etc.)			
Head (size, shape, sutures, fontanels, VP shunt, etc.)			
Eyes (EOM, PERLA, Red reflex, discharge, conjunc., nystag., strab.)			
Ears (TM, discharge, etc.)			
Nose (patency, turbinates, congestion, nares, etc.)			
Oropharynx (teeth, tongue, gums, tonsils, etc.)			
Neck (supple, trachea, thyroid)			
Nodes (axillary, cervical, inguinal, submandibular, etc.)			
Chest (symmetry, pectus excavatum)			
Lungs (wheezes, rales, rhonchi, retractions)			
Heart (murmur, S_1S_2, thrills, rubs)			
Abdomen (organomegaly, hernia, masses, tender)			
Genitalia Anorectal (testes, labia, hydrocele, vagina, discharge)			
Spine (straight, scoliosis, kyphosis)			
Extremities (ROM, gait, feet, ortalani)			
Neuromuscular (DTR's, strength, tone, clonus, spasticity)			
Reflexes (ATNR, moro, Parachute, Babinski, root, suck, landau)			

SUMMARY OF RECOMMENDATIONS, CARE GIVEN:

FINAL IMPRESSION:

The follow-up program in Iowa was developed to meet the state's unique characteristics. Other high-risk follow-up programs around the country were surveyed to determine variations in approaches. Information gathered from four other programs are summarized in table 8.

These programs represent varied geographical regions, size, purpose, and funding. Given local needs and resources, diversity is highly appropriate. Yet, each program should build upon the results of others and not unnecessarily duplicate studies. Shared knowledge concerning what works and what does not work is likely to yield considerable savings in cost and frustration. The who, what, where, and when of follow-up must be reviewed and discussed, then tailored to local or regional needs.

The U.S. Department of Health and Human Services (Division of Maternal and Child Health), in collaboration with private groups such as the National Center for Clinical Infant Programs, recently has worked to provide forums for communication and collaboration about the needs of high-risk infants and their families. Such efforts undoubtedly will lead to a sense of "best practice" for the delivery of services.

Table 8. A comparison of five high-risk infant follow-up programs

Comparison of Iowa High-risk Follow-up Program to Other Programs

Program	Gallatin Co. High-risk Infant Follow-up Program Bozeman, Montana	Perinatal Follow-Through Program of Southeastern Wisconsin Milwaukee, Wisconsin	Special Care Nursery Follow-up Program Chicago, Illinois	Iowa High-risk Infant Follow-up Program Iowa City, Iowa	High-risk Newborn Follow-up New York, New York
Affiliations	Gallatin Co. Health Department Bozeman Deaconess Hospital Easter Seals Private Physicians	St. Joseph Hospital Milwaukee County Medical Complex Mount Sinai Hospital SE Wisconsin Perinatal Care System	Rush-Presbyterian-St Luke's Medical Center	The University of Iowa Hospitals and Clinics St. Luke's Hospital, Cedar Rapids Iowa Methodist Medical Center, Des Moines Iowa Mobile and Regional Child Health Specialty Clinics	Bellevue Medical Center New York University
Predominant Geographical Area	Rural	Urban/Rural	Urban	Rural/Urban	Urban
Funding	City/County Taxes	Affiliated Hospitals Wisconsin Department of Public Instruction (M&CH block grant) Curative Rehabilitation Center	Hospital	M&CH Federal Division Robert Wood Johnson Foundation State of Iowa Legislature Affiliated Hospitals	Federal
Cost	No charge	No charge/ Third party	PT $35 Psych $55	No charge	$7-17
Intensive Care Nursery Capacity	7	87	41	161	24
Entry Criteria	Habel Scoring System Pre/Intra Partum >20 Neonatal >10 At Risk for Hearing Impairment (JCH Criteria)	BW < 1,500 grams GA <32 weeks Vent + <2,000 grams CPAP + < 1,800 grams Asphyxia Seizures Meningitis Unusual Behavior in Nursery Exchange Transfusions Hypoglycemia Drug Withdrawal PDA Congenital Infection Congenital Anomalies SGA Request of Neonatologist	<1,200 grams	<1,500 grams RDS CNS infection Asphyxia Hypoglycemia Hypotonia Vent >2 hours Seizures Other	<1,800 grams Hyperbilirubinemia—requiring exchange transfusion RDS Asphyxia Congenital Anomalies

Program	Gallatin Co. High-risk Infant Follow-up Program Bozeman, Montana	Perinatal Follow-Through Program of Southeastern Wisconsin Milwaukee, Wisconsin	Special Care Nursery Follow-up Program Chicago, Illinois	Iowa High-risk Infant Follow-up Program Iowa City, Iowa	High-risk Newborn Follow-up New York, New York
Tests	DDST DASE Milani-Comparetti Audiology	DDST Milani-Comparetti Denver Eye Test Speech Questionnaire Audiometry Physical Exam	Physical Exam Bayley Scales Stanford Binet Inventory of Maternal Stress & Family Resources Ophthalmology (at 1 year) Audiology (at 8 + 24 months)	4-30 months DDST Physical Exam Interview 5 years Psychometric Evaluation Pediatric Examination of Educational Readiness (PEER) Psychosocial Questionnaire Physical Exam 8 years Undetermined	DDST Physical Exam Ophthalmology (3 mo., 6 mo.) Audiology (9 mo.) Gesell Cattell <3 years Wechsler >3 years Vineland Scale of Social Maturity Carey Temperament Scale by Psychologist in clinic or request of neonatologist
Core Personnel	Nurses PHN OB Nurses Audiologist	PNP PT Audiologist (Neonatologist as a consultant)	Neonatologist Psychologist Nurse PT Coordinator	PNP supervised by neonatologist and developmental pediatrician Pediatrician Psychologist Undetermined	Neonatologist Nurse Social Worker
Frequency	Minimum 2 weeks, 3, 6 months, 1,2,3,4,5 years, 6,7 years (phone only), 8 years	4-6 months (corrected age) 15 months (corrected age)	2 weeks, 4, 8, 12, 18, 24 months (corrected age) and yearly thereafter	4, 9, 18 30 months (chronological age); 5 years, 8 years	0-6 months (every month); 6-18 months (every 3 months); 18 months-3 years (every six months); 3-6 years (every year)

Maryland

MARYLAND'S HIGH-RISK INFANT FOLLOW-UP PROGRAM

Maryland is one of the ten original States in the National 0-3 Project Network

Since 1983 Maryland has had a formal State Advisory Committee for review of the 0-3 population, issues and needs. The "Maryland Advisory Committee Project 0-3" has established authority under the aegis of the Preventive Medicine Administration, State Department of Health and Mental Hygiene. This committee, chaired by Polly Roberts, M.D., Director, School Health Program, State Department of Health and Mental Hygiene, has a defined structure, with interagency membership and parent representation.

In July, 1982, Eric Fine, M.D., M.P.H., then Director of the Division of Infant, Child and Adolescent Health, currently Director, Preventive Medicine Administration, Maryland Department of Health and Mental Hygiene, appointed Misbah Khan, M.D., M.P.H., Associate Professor of Pediatrics, University of Maryland as a consultant with specific responsibility to "develop and coordinate infant follow-up, determine long-term effectiveness of neonatal regionalization, identify a practical assessment method for graduates of neonatal intensive care units (NICUs), and work with local health departments, community agencies and private child health providers to coordinate local support services for high risk neonates and their families."

Since July, 1983, a grant-funded demonstration project under this mandate has been operational in three select areas of the state of Maryland: Baltimore City, Baltimore County, and Washington County, representing urban, suburban and rural areas. This project is conducted by the University of Maryland's Department of Pediatrics, in collaboration with three local health departments, six Regional Intensive Care Nurseries and their respective institutions, the University of Maryland Department of Epidemiology and Preventive Medicine, the University of Maryland School of Nursing, and the Regional Center for Infants and Young Children of Maryland, Virginia and the District of Columbia. The goal of the Maryland High Risk Infant Follow-Up Program is to establish interagency coordination and systematic follow-up of high risk infants, in their home communities, after discharge from Maryland Regional Intensive Care Nurseries. The aim is to ensure that all infants at risk and their families receive early and ongoing support, including assessment and intervention, through a coordinated network of community resources.

Principles and philosophy underlying development of the Maryland High Risk Infant Follow-Up Program

1. *The Health Department, at the state and local level, is the designated lead agency* for the coordination of care, with responsibility for interagency collaboration and ongoing services including systematic follow-up, assessment, referral, data collection and reporting.
2. *The community health nurse* is the key professional with designated responsibility for following infants.
3. *Staff training* is a prerequisite which enables the community health nurse to acquire proficiency and confidence in the assessment of the child's growth, development and environment; in intervention, with referral as necessary; and in the utilization of local interagency resources.
4. *A comprehensive approach* is critical to the care of high risk infants. This approach is reflected in the program's assessment at regular intervals of:
   - the infant's growth, development and functioning
   - parental competence
   - parent/child interactions
   - family functioning
   - the home environment
5. *The Maryland program supports the right of every child to receive the full benefit of appropriate and timely services in order to attain optimal development and quality of life* as the basic purpose of the program. Nurturance of the infant demands an approach that is patient, caring, tender and individualized and yet provides high quality, specialized and technical care as needed. Parent and family support are essential elements of ongoing supervised care.
6. *Accountability* requires data collection with ongoing

evaluation of the program and outcome in terms of infant health measures and service objectives being met.

In addition to, and finely balanced with, the highly technological and mechanized care, there must be a tenderness of thought and expression, a caring and individualized involvement on the part of professional caretakers, both in the ICN and after discharge, such that nurturance of the infant is the rule with ongoing supervised care, as well as parent and family support. Our thinking, impersonal attitudes, or choice of words that convey harsh meaning (e.g. tracking: tracking down a criminal, tracking as in hunt, etc.) can unintentionally rear attitudes that add an element to care that may not convey our true intent of service with nurturance, acceptance and support of the infant and family for optimal growth and development of both.

Essential components of the Maryland High Risk Infant Follow-Up Program

1. Staff training for community health nurses in assessment, intervention, referral, and use of local community resources
2. Follow-up procedures
   a. Obtain parental consent for follow-up
   b. Identify infant
   c. Notify local health department
   d. Make initial home visit and home visit after infant is discharged from NICU
3. Assessment of:
   a. Infant's physical, cognitive, emotional, neurological and social growth, development and functioning
   b. Parental competence
   c. Parent-child interaction
   d. Family functioning
   e. Home environment

The assessment protocol uses select instruments, i.e., the Brazelton Neonatal Behavioral Assessment Scale, the Family Apgar Scale, the Greenspan-Lieberman Interaction Scale, and the Caldwell Home Scale.

4. Reporting system:
   a. computer forms are used for data collection

Collaboration: Interagency and multidisciplinary structure:

A significant part of the Maryland program is the nature of its structure and collaboration between multiple institutions, agencies and local community service providers.

The FY 85-86 program is sponsored by the Preventive Medicine Administration of the Maryland Department of Health and Mental Hygiene. It is conducted by the University of Maryland Department of Pediatrics in collaboration with the University of Maryland Department of Epidemiology and Preventive Medicine, the University of Maryland School of Nursing, the Regional Center for Infants and Young Children of Maryland, Virginia, and Washington, D.C., three local Health Departments, and six Baltimore institutions with the Regional Neonatal Intensive Care Units. The assessment protocol is reviewed and approved by the Human Volunteers Committee of the University of Maryland, as well as by the Institutional Review Boards of the six NICU hospitals, i.e., Johns Hopkins University Hospital, Mercy Hospital, St. Agnes Hospital, Sinai Hospital, and the Francis Scott Key Medical Center. Parents and referral agencies such as the Department of Social Services, child protective service agencies, local departments of special education, Child Find Program, private physicians and child health clinics are involved in community health nurses' day-to-day activities, consultations and referrals.

Future plans

In FY 1986, training will be expanded to include all child health community health nurses in participating local health departments.

Summary:

The FY 1984-85 project established a network of interagency, interdisciplinary and institutional collaboration, with joint planning and implementation. A standard approach has been developed for the follow-up and assessment of high risk infants. This was a direct outcome of the interest and commitment of both the Project staff and the State Health Department sponsors. This collaborative network with interagency commitments is essential for continuity and coordination of services.

The Maryland program sponsored by the Preventive Medicine Administration, State Department of Health and Mental Hygiene is planned and implemented with ongoing review by the University of Maryland Department of Pediatrics in collaboration with the University of Maryland School of Nursing; the Regional Center for Infants and Young Children of Maryland, Virginia and Washington, D.C.; the University of Maryland Department of Epidemiology and Preventive Medicine; the local Health Departments of Washington County, Maryland represented by Dr. James Bond, Director of Health Services and Ms. Linda Humbert, Director of Nursing; Baltimore County, Maryland represented by Dr. William Anderson, Director of Child Health and Ms. Jane Galbraith, Director of Nursing; and the Baltimore City Health Department represented by Dr. Rupla Eshai. Neonatologists and staff from six Regional Neonatal Intensive Care Units and practicing pediatricians in the project areas have all contributed to the establishment and continuity of the Maryland program.

Maryland Special Infant Follow-Up Program

Maryland Department of Health and Mental Hygiene

Dear Parent:

Your baby will receive special care in the intensive care nursery. As a parent, you are the most important person in your baby's life and this is a time of worry and concern for you and your family. You may have questions about your baby's care, or you may need help after you leave the hospital.

The Maryland Department of Health and Mental Hygiene, through your local health department has recently started a program to help families of infants admitted to the intensive care nursery. This program is for babies whose parents wish to participate. The program is in addition to your baby's regular health care as provided by your baby's doctor.

With your consent, and in consultation with your baby's doctor, a specially trained pediatric community health nurse will meet with you, and see your baby in the hospital and at home. After your baby leaves the hospital your nurse will see both you and your baby, either in the local health department clinic or in your home, by appointment. Later, the baby's progress will be noted by the nurse at 4, 8 and 12 months of age.

How Will This Program Help Me and My Baby?

* The program will help you understand your baby's growth and development.
* The program will help identify your baby's special needs.
* Your community health nurse will assist you in obtaining the necessary services for your baby as early as possible.
* Your nurse will answer any questions about the program or services for you and your baby in your community.

How Does The Maryland Special Infant Follow-Up Program Work?

* The community health nurse will interview you to determine what your needs are and to answer questions you may have.
* The nurse will provide you with information to increase your knowledge of your baby's growth and development as well as any special needs.
* The community health nurse will discuss your baby's growth and development and observe your baby's interactions.
* With your consent, the nurse will share this information with your baby's doctor or the clinic.
* The nurse will be able to inform you about service resources in your community, as well as about parent groups with similar concerns, who may be of help to you.

How Will The Information Obtained From Parents Be Used?

* All information will be strictly confidential.
* The information you provide will be used for planning services for mothers and babies throughout the State of Maryland.
* Your participation will help to plan for continuing services and programs and to identify the most important needs of infants and their families.

Can I Withdraw From The Program At Any Time?

* Yes. Your participation is entirely voluntary. We hope you will join us in this program, and help to establish necessary service programs for mothers and babies in Maryland.

Can I Obtain More Information About The Program?

* If you reside in Baltimore City, Baltimore County or Washington County, please call the following numbers for additional information about the Maryland Special Infant Follow-Up Program:

Community Pediatric Center, University of Maryland 528-3257

Misbah Khan, M.D., M.P.H. (Project Director)
Sue Poisson, M.A.
Dale Hart, B.S.
Eva Hollingsworth, M.S.W.

Baltimore City Health Department . . 396-4463

Rupla Eshai, M.D.
Linda Nickless, R.N.

Baltimore County Health Department . 494-3725

William Anderson, M.D.
Joanne Clark, R.N.

Washington County Health Department .791-3247

James Bond, M.D., M.P.H.
Linda Humbert, R.N., M.P.H.

Department of Health and Mental Hygiene
. . . . 383-7510
. . . . 383-2667

Bella Caplan, R.N., M.S.
Peggy Harvie, R.N., M.A., C.P.N.P.
Joan Stine, M.S., M.H.S.
Pearl Shiling, M.S.W., M.P.H.

North Carolina

North Carolina High Priority Infant Program

Guidelines and Procedures

Department of Human Resources
Division of Health Services
Maternal and Child Care Section

July 1, 1984

NORTH CAROLINA
HIGH PRIORITY INFANT PROGRAM

I. Introduction

In July 1979, North Carolina embarked on a statewide effort to identify and track infants at risk for developmental delay and assure they receive medical supervision during the first year of life. The High Priority Infant Program (HPIP) has been successful in identifying these high risk infants, but was not designed to provide data on the health status of the infants tracked. Consequently, the impact of this program has been difficult to measure.

In addition to the shortcomings in the area of evaluation, two general areas of concern have been expressed. First, the risk criteria are too broad and lead to the unnecessary identification and tracking of too many infants. Secondly, limiting the identification period to the newborn nursery is too restrictive since many infants can become high risk after discharge.

In response to these concerns, a task force was formed with representation from the Maternal and Child Health Branch, Developmental Disabilities Branch, local health departments and Developmental Evaluation Centers. This group, working in close cooperation with the Fetus and Newborn Committee of the North Carolina Chapter of the American Academy of Pediatrics, has developed the new program format detailed in the following guidelines.

The task force set out to revise the program giving consideration to the shortcomings and concerns described above. Moreover, the task force members sought to propose a program format which reflects a commitment to improved and appropriate early intervention and follow-up of identified infants and their families. The increase in required

surveillance and guidance to families of children at the highest medical risk exemplifies this commitment. The intention is to enhance the program's original functions by embellishing the criteria for enrollment and by re-emphasizing the developmental assessment and intervention services needed throughout the first year of life.

II. Mission

1. To assure that infants at risk for developmental delays and other handicaps have maximum opportunity to reach their developmental potential.
2. To enhance infant health care for those at risk, through a system of identification, tracking, home visiting, and referral for developmental assessment and early intervention.
3. To document infant and perinatal care services, and to better plan for child health and habilitative services, during the preschool years through establishing an information system.

III. Goals

1. To identify, as early as the time of newborn hospitalization, infants at risk for developmental delay and handicapping conditions.
2. To enroll infants so identified into the High Priority Infant Program.
3. To track all enrolled infants to assure that they are entered and remain in child health supervision through at least the first year of life.
4. To identify among those enrolled, a subgroup of infants at especially high risk for developmental delays and handicapping conditions.
5. To make regular home visits during the first year of life of those infants at highest risk in order to assess the home environment, to assure proper developmental screening and to assure that these infants

will be returned to an infant follow-up clinic or a developmental evaluation center at one year of age corrected for gestation.

6. To collect information on enrolled infants from tracking and home visiting efforts, and from one year developmental assessments, in a manner that is consistent statewide.
7. To assess that information for evaluation and planning of newborn, infant, and preschool services.

IV. Planning Local Programs

Implementing these changes at the local level will require close cooperation among the local health department, private physicians, Developmental Evaluation Center, neonatal intensive care follow-up clinics, Early Childhood Intervention Programs, other evaluation programs, and hospitals serving each county. As the recipient of funds for the program, the local health department must take the lead locally in assuring these changes are made cooperatively. The purpose and frequency of home visits must be discussed with the private physicians in the community by the contact nurse in the health department. The Denver Prescreening Developmental Questionnaire and Developmental Screening tests should be done at the discretion of the private physician for those high priority infants receiving care in the private sector. Good communication among the key agencies and individuals involved in this program will be essential during this period of transition. The guidelines are intended to be flexible and serve as a base for local negotiations with community physicians. Assistance in local planning efforts will be available from the staff of the Maternal and Child Health Branch and Developmental Disabilities Branch.

V. The following diagram graphically explains the recommendations and/or protocol for the High Priority Infant Program.

HIGH PRIORITY INFANT IDENTIFICATION AND TRACKING PROTOCOL

HIGH PRIORITY CONDITIONS	Identification	Consent	Service	Corrected Birthdate: 2 weeks Post Disch.	1 mo.	3 mo.	6 mo.	9 mo.	12 mos.
A. CONDITIONS 1. ≤1500 gms. 2. Intracranial hemorrhage 3. Meningitis 4. Seizures 5. Neurological abnormality Due To: Perinatal asphyxia	In Nursery	Parent and M.D.	HOME VISIT	Required R.N.		Required	Required	Required	
			TRACKING			Required	Required		Required
			DEV. GUEST			Required		Required	
			DENVER				Required		
			DEV. ASSES.*					Ref.for 12 mo. Asses	Required Dev. Asses
			a. Review of home visits and dev. screening summaries b. Bayley - MDI - PDI c. MD Neurological d. Hearing e. Vision						
B. CONDITIONS 1. Age: Mother 14 yrs. or less 2. Birthweight: 3 lbs. 5 oz. - 4 lbs. 8 oz. (1500-2000 gms.) 3. Gestational age: 34 weeks or less 4. Hyaline membrane disease (RDS) 5. Aspiration pneumonia 6. Other pneumonia 7. Recurrent apnea 8. Bilirubin ▶ 20 mg/dl 9. Other serious neonatal infections 10. Persistent fetal circulation 11. Neural tube defect 12. Other major birth defect or syndrome 13. Serious environmental, social, or parenting disturbance	In Nursery	Parent and M.D.	HOME VISIT		Recom.	Recom.	Recom.	Recom.	
			TRACKING			Required	required		Required
			DEV. GUEST			Recom.		Recom.	
			DENVER				Required		
			DEV. ASSES.*						Dev. Asses as needed
				2 weeks Post Ident.					
C. CONDITIONS All Conditions in A & B not identified in nursery 14. Vision impairment 15. Hearing impairment 16. Failure to thrive 17. Developmental delay	Post Disch.	Parent and M.D.	HOME VISIT	Recom.	Recom.	Recom.	Recom.	Recom.	
			TRACKING			Recom.	Recom.		Recom.
			DEV. GUEST			Recom.		Recom.	
			DENVER				Required		
			DEV. ASSES.*						Dev.Asses as needed

* Referral for developmental assessment to DEC/ and/or follow up clinic can be made at any point on the continuum

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VI. Identification

Conditions developed by the Maternal and Child Health Branch and the Fetus and Newborn Committee of the North Carolina Chapter of the American Academy of Pediatrics should be adopted without modification. The use of the conditions will lead to a program for a standardized assessment to be done on Group A infants at one year (corrected birth date by gestational age determined by E.D.C. or Dubowitz Examination). The outcome of these assessments would enhance the possibilities for an evaluation of this program.

Three categories for identification of high risk infants have been established. Group A would include infants with birthweight less than 1500 grams, intracranial hemmorrhage, meningitis, seizures and neurological abnormalities. Group B would be comprised of infants falling under the HPIP original risk criteria with some changes. First, maternal age would be dropped from under 17 years to under 15 years as a risk factor. Secondly, birthweight as a risk factor would be lowered from 2500 grams to 2000 grams. Thirdly, gestational age would be lowered from 36 to 34 weeks or less. Also, persistent fetal circulation would be added as a new risk factor and the area of serious environmental, social, or parenting disturbance will be more clearly defined. Group C is an optional category which includes infants identified post-discharge with any condition listed for Group A or B. Infants failing to thrive, infants exhibiting vision and/or hearing impairment and developmental delays would fall in this category.

On a regular basis, preferably weekly, hospitals will forward to the local health departments the completed identification record (DHS 2682, Rev. 7-1-83) for those infants enrolled in this program. For completing

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Identification Record (DHS 2682, Rev. 7-1-83) see the instructions on the back of the form. (See appendix for sample of DHS 2682).

A record is completed for each infant who meets at least one of the high priority conditions as soon as possible after the condition(s) are identified. The identification record should be completed by hospital personnel and/or local health department staff. High priority identification records for infants transferred to other hospitals should be completed by the staff of the hospital to which the infant is transferred.

Parents must be informed verbally and in writing regarding the nature of the program before proceeding with enrolling infants identified by attending physicians or their designees as having a high priority condition(s) Written permission and to release information must be obtained from the parent and witnessed by the individual obtaining permission before the transmission of personal and medical information to the local health departments. The details of the procedures for obtaining permission must be worked out at the individual hospital level. The signature of the attending physician or designee must also be obtained on the identification record.

The original copy of the identification record (DHS 2682, Rev. 7-1-83) should be retained by hospital where infant is identified. Copies 1 and 2 should be forwarded to the local health department. For resident births, the health department forwards copy 1 to the primary medical provider (private physician) and retains copy 2. For non-resident births, the health department forwards copies 1 and 2 to the local health department where infants reside. The health department where the patient resides performs the same steps as outlined above.

HOSPITALS CARING FOR INFANTS IN GROUP A SHOULD NOTIFY THE LOCAL HEALTH DEPARTMENT OF THE COUNTY OF RESIDENCE WHEN AN INFANT IS DISCHARGED SO THAT PREPARATION FOR HOME VISITS CAN BE MADE.

VII. Home Visiting:

Group A infants shall receive a home visit by an R.N. within two weeks of discharge. Home visits which will also be made at 3, 6, and 9 months may be delegated by the R.N. Home visits will be done at the recommended intervals as determined by corrected birthdate. The tracking personnel will contact the local physician providing the infant's care to discuss implementation of any home visits.

The following are specific objectives around which an overall home assessment should be done:

A. Determining social support and family adjustment to the newborn;

B. Determining ability and potential for the family to provide or obtain proper health care;

C. Determining ability and potential for the family to provide proper infant care and stimulation;

D. Determining potential for abuse and neglect;

E. Determining the areas of need for nurse/health department intervention either directly or by referral. (This information will accrue directly from A, B, C, D.)

A Home Visit Worksheet has been formulated (see appendix) which addresses these objectives. This worksheet may be utilized in part or in whole by the R.N. or the delegated person during the home visit. The worksheet is not intended to limit the interviewer to the items listed. Areas to be explored depend on the response of the interviewee, interviewer's knowledge of the situation and the interviewer's own style.

In this way, one is able to identify specific areas of need, provide appropriate guidance, and develop a plan of action for referral and/or intervention utilizing the SOAP format on the POHR notes. Prior to the twelve-month assessment, a summary of the specific areas of need will be submitted to the agency responsible for the assessment.

Although the high priority nurse has responsibility for home visiting and the home assessment summary, staff of the DEC or Neonatal Intensive Care Clinic have the option to participate in the process according to local negotiations. High Priority nurses may call upon DEC or NIC Clinic for assistance in collecting or interpreting home assessment data. Referral to Early Childhood intervention Programs should also be considered according to each child's needs.

For Group B infants, a home visit within one month of discharge is highly recommended. The R.N. may delegate this visit. Home visits at 3, 6, and 9 months are left to the judgement of the R.N.

Home visits for Group C infants are left to the judgement of the R.N.

VIII. Tracking

On a monthly basis health departments will send to community physicians (primary medical providers) notifications of high priority infants who were listed in the hospital as their patients, and who are currently three to four, six to seven, and twelve to thirteen months old. Tracking will be done at these intervals as determined by the corrected birthdate. Tracking Record (DHS 2683, Rev. 7-1-83) will be used for this notification which includes instructions for completing on the back. (See appendix for sample of DHS 2683). Required tracking of infants in Group A and B will be done at three (3), six (6) and twelve (12) months of age. Tracking is optional for infants in Group C.

On the tracking record (DHS 2683, Rev. 7-1-83) the primary medical provider will complete #8 - 11 and return completed record to the tracking nurse requesting this information. If the primary medical provider is caring for the child regularly, the appropriate space should be checked. If the primary medical provider is not seeing the child regularly, the appropriate space on the record should be checked. The appropriate space which indicates the reason why the child is not under care is also checked. If a visit to the family by the Public Health Nurse is requested, the appropriate space should be checked and reason for request provided.

If the primary medical provider has done the Denver Pre-screening Developmental Questionnaire and/or Denver Developmental Screening, the appropriate space and/or spaces should be checked.

If the infant is referred to a Developmental Evaluation Program, PACT, ECIS and other Intervention Programs, the appropriate space and/or spaces should be checked.

Results of the public health nurse's visit should be recorded in the appropriate space. The local health department may attach a copy of the nursing notes from the POHR pertaining to this home visit. A copy is sent to the primary care provider.

IX. Screening and Testing

The Denver Prescreening Developmental Questionnaire and the Denver Developmental Screening Test will be done at the suggested intervals as determined by the corrected birthdate.

Group A Infants

A Denver Prescreening Developmental Questionnaire (PDQ) is required at 3 and 9 months. A Denver Developmental Screening Test (DDST) is required at 6 months of age.

Group B Infants

A Denver Prescreening Developmental Questionnaire (PDQ) is recommended at 3 and 9 months. A Denver Developmental Screening Test (DDST) is required at 6 months of age.

Group C Infants

A Denver Prescreening Developmental Questionnaire (PDQ) is optional for this infant group. A Denver Developmental Screening Test (DDST) is required at 6 months of age.

Refer to specific manuals for details for administering the PDQ and DDST.

Summaries of the infant's performance on the DDST and parental responses on the PDQ will be submitted to the agency responsible for the twelve month follow-up assessment.

X. Developmental Evaluation

Evaluation of clinically identified problems and the development of appropriate intervention strategies are integral to the High Priority Infant Program. Appropriate evaluation of infants who are enrolled in the High Priority Infant Program should occur as soon as possible when disabling conditions are suspected - regardless of the category into which the condition falls. Infants whose conditions fall into Category A are eligible to receive a standard follow-up assessment at twelve months of age through one of the State's Developmental Evaluation Centers or one of the hospital-affiliated neonatal intensive care follow-up clinics. Developmental Evaluation Centers and neonatal intensive care follow-up clinics should use the "Protocol for Twelve month Follow-up Assessment" to implement the standard assessment.

A. Evaluations Needed Before the Twelve Month Follow-up Assessment

Several neonatal intensive care follow-up clinics have routine schedules for evaluating infants throughout the first year of life. These schedules are not affected by the changes in the High Priority Infant Program. Likewise, infants with obvious disabilities who are not served by a neonatal intensive care follow-up clinic should be referred to a Developmental Evaluation Center for evaluation as soon as possible. Early referral should be determined on the basis of abnormal or questionable results as established by the protocols for the Prescreening Developmental Questionnaire and the Denver Developmental Screening Test. Infants who cannot focus their eyes on objects should be referred for an ophthalmologic evaluation. Infants who have a condition associated with hearing impairment as established by the American Academy of Pediatrics should be referred for hearing screening.

Developmental Evaluation Centers should be prepared to schedule assessment for these infants as soon as possible after referral. All relevant information about an infant's condition should be forwarded to the Developmental Evaluation Center of referral with written parental permission as soon as possible.

B. Standard Twelve Month Follow-up Assessment

All infants enrolled in the High Priority Infant Program who have conditions in Category A should receive the standard twelve months follow-up assessment.

The referral of infants to Developmental Evaluation Centers for the standard twelve month follow-up assessment should occur as soon as possible after a child is enrolled in the High Priority Infant Program, but no later than at nine months of adjusted gestational age. As with assessments needed before twelve months of age, the local agreements for referral to the appropriate Developmental Evaluation Center should be followed. The public health nurse has responsibility for providing parents of the identified infant with appropriate information about the Developmental Evaluation Center to which they will be referred. Permission for staff of Developmental Evaluation Centers to obtain information from and to release information to relevant agencies should be obtained early in the process whenever possible. Public health nurses may assist staff of Developmental Evaluation Centers to obtain permission according to local agreements. The twelve month follow-up assessment should occur preferably at twelve months adjusted gestational age, but no earlier than eleven months or no later than thirteen months, whether or not they received prior assessment.

Infants who are to receive a standard twelve month follow-up assessment at neonatal intensive care follow-up clinics may be scheduled according to the procedures of those clinics.

"Protocol for the Twelve-Month Follow-up Assessment"

The twelve month follow-up assessment represents an examination of select developmental dimensions for each child who meets at least one of the criteria in Category A. The collection and analysis of information about these dimensions are related to the following objectives:

(a) Each infant's status can be compared to their expected, adjusted chronological age norms.

(b) Each infant's assessment establishes the baseline for following their progress into subsequent years and for facilitating parental and professional understanding of each child's unique needs.

(c) Each infant's findings provides a profile of their outcome subsequent to the treatment they receive during the first year of life.

(d) The experience of the developmental assessment provides each family with the opportunity to learn important information about their child's needs for caregiving and/or special treatment.

Several procedures in the twelve month follow-up assessment are standardized in order to facilitate comparison of children by groups, according to chronological age, geographical distribution, and developmental condition. The assessment is not limited to these uniform procedures, however, and may be expanded by clinicians to meet the individual needs of each child. At the minimum the assessment includes:

1. Review of Medical History and Home Visit and Developmental Screening Summaries

Medical History

Previous summaries and reports about perinatal conditions, labor and delivery, intensive care nursery course, and discharge should be reviewed. Primary health care status should be considered along with remarkable events such as injuries or infections which have occurred during the first year of life.

Home Assessment

The summary of remarkable conditions found in the home assessment conducted by the public health nurse and/or other providers should be reviewed. The essential dimensions to be considered include:

(a) Social support and family adjustment

(b) Ability and potential for the family to provide or obtain proper health care

(c) Ability and potential for the family to provide proper infant care and stimulation

(d) Potential for abuse and neglect

(e) Areas of need for local health department intervention either directly or by referral.

Developmental Screening

Summaries of the infant's performance on the Denver Developmental Screening Test (DDST) and parental responses on the Prescreening Developmental Questionnaire (PDQ) should be reviewed. A record of the DDST screening which was conducted at six months of age (corrected for gestation) may be interpreted as "Normal", "Questionable", or"Abnormal", according to DDST Reference Manual (1975), Page 12.

The results, when considered with the results of the PDQ may provide an indication of the infant's developmental progress from the third to the ninth months of life. The PDQ also provides a measure of the parent(s)' perceptions of the child's development. This screening information should be compared with reports of any in depth developmental assessments which may have been conducted prior to the twelve month assessment.

2. Developmental Assessment: Bayley Scales of Infant Development

Standard administration of the Bayley Scales of Infant Development should be completed between the eleventh and thirteenth month of life (corrected for gestation). Results of the administration of the Mental Scale should be expressed as the Mental Developmental Index (MDI) and the Motor Scale as the Psychomotor Development Index (PDI). The Infant Behavior Record, although not required for statistical reporting, may also

be administered to provide a more comprehensive evaluation of infant development. Age equivalents should be computed for infants whose mental Development Index or Psychomotor Development Index is equal to or less than 50.

3. Neurological Examination

In addition to the neurological examination, the measurements of head circumference, weight, and height should be performed and should be adjusted to gestational age in order to obtain some impression of general development.

The neurological examination should address the following areas:

a. Muscle tone (in all four extremities)

b. Protective Responses

c. Station

d. Gait

e. Sensory Status

f. Deep Tendon Reflexes

g. Clonus

h. Cranial nerves (including a funduscopic and otoscopic examination)

4. Vision Screening

In addition to the funduscopic examination, which is conducted as part of the neurological examination, vision should be further assessed through the utilization of confrontational visual field testing.

Referral to an ophthalmologist should be based on the individual judgement of the examiner. If there is any question of visual impairment, or the child has a history of extreme prematurity or oxygen therapy and has not been seen by an ophthalmologist, then such a referral should be made.

5. Hearing Screening

In addition to the otoscopic examination which is conducted as part of the neurological examination, hearing should be assessed through the utilization of the auditory localization skill development technique. The technique involves a visual distraction followed by controlateral presentation of an auditory stimulus.

In addition to the auditory localization procedure, receptive and expressive language skills should be assessed by means of the Receptive-Expressive Emergent Language Scale (REEL). Administered to the parents or primary caregivers, the REEL has three receptive and three expressive items at monthly intervals during the first year. Review of feeding and oral motor skills to supplement the REEL should also be administered.

Children whose hearing and language tests are questionable or abnormal should be referred for more sophisticated audiological testing. Also, such referral should be made for those children who appear to be severely handicapped. Special attention should be paid to children who have a condition listed among the high risk factors for hearing impairment as established by the American Academy of Pediatrics.

C. Reporting the Results of the Twelve Month Follow-up Assessment

Measures of each infant's performance on the twelve month follow-up assessment are to be reported on a standard form to be provided by the Developmental Disabilities Branch of the Division of Health Services. This data will be filed and cross-tabulated to provide routine summaries on the population of children with Group A conditions, as well as for special studies.

Results of each evaluation performed on a child should be sent to the local health department as well as to the private physician. Developmental Evaluation Center staff should secure permission to release information by the time of the parent interpretive conference or parent planning session in

order to expedite the process. Developmental Evaluation Center staff are encouraged to confer with public health nurses and private physicians to synthesize findings and to develop intervention plans.

XI. Collection and Transmission of Data

Effective July 1, 1983, data on the identification, tracking, PDQ/DDST, and home visits will be submitted by the local health departments through the Maternal and Child Care Information System. Identification, tracking, and home visit information should be reported on DHS 3108 (PATIENT DATA RECORD) at three, six, and twelve month tracking intervals. Information on each infant's high risk conditions, hospital of birth, and hospital transferred to should be submitted at the three month tracking interval. Tracking data (e.g. home visits, developmental screenings, receiving care, etc.) reported should include what has taken place since the last tracking. Data on the standardized twelve month follow-up assessment will be collected in the Developmental Evaluation Center Information System. A common patient ID numbering system will allow the merging of data from these two information systems. Reports will be provided to the local health departments and DEC's on a quarterly basis.

We will have the capability to generate reports on Group A infants by county of residence, hospital of birth, and hospital of transfer.

Appendix 1

North Carolina Department of Human Resources
Division of Health Services

HIGH PRIORITY INFANT IDENTIFICATION

1. Child's Last Name | First Name | MI

2. Patient Number — Check digit [ ] [ ] [ ] [ ] - [ ] [ ] [ ] [ ]

3. Date of Birth: [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] — Month | Day | Year

4. Race: [ ] 1. White [ ] 2. Black [ ] 3. Am. Indian [ ] 4. Other

5. Sex: [ ] 1. Male [ ] 2. Female

6. County of Residence:

7. Mother's Last Name | First Name | MI

8. Address: Street or Route # | Town | Zip Code

9. Telephone:

10. Hospital of Birth:

11. Hospital transf. to:

12. Corrected Birth Date:
Weeks Gestation 40
Enter Actual Gestational Age in weeks at birth by EDC or Dubowitz -
Weeks Pre-term
Enter Actual Birth Date -
Corrected Birth Date: [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] — Month | Day | Year

(Mark [X] Appropriate Codes)

13. Code A. IDENTIFIED NURSERY CONDITIONS

Birthweight: 0 - 1500 gms.

A1a ( ) 0 - 500 gms.
A1b ( ) 501 - 600 gms.
A1c ( ) 601 - 700 gms.
A1d ( ) 701 - 800 gms.
A1e ( ) 801 - 900 gms.
A1f ( ) 901 - 1000 gms.
A1g ( ) 1001 - 1250 gms.
A1h ( ) 1251 - 1500 gms.

A02 ( ) Intracranial hemorrhage
A03 ( ) Meningitis
A04 ( ) Seizures
A05 ( ) Neurological abnormality due to perinatal asphyxia

14. Code B. IDENTIFIED NURSERY CONDITIONS

Serious Environmental, Social, or Parenting Disturbance:

B1a ( ) Single parent with problem of family support
B1b ( ) Parent with incapacitating medical/mental handicap
B1c ( ) Parent with history of alcohol or drug abuse
B1d ( ) Mother demonstrates difficulty in maternal/infant interaction
B1e ( ) No prenatal care (drop-in)

B02 ( ) Mother 14 years or less
B03 ( ) Birthweight 1501 - 2000 gms. (3 lbs. 5 Oz. - 4 lbs. 8 oz.)
B04 ( ) Gestational age of 34 weeks or less
B05 ( ) Hyaline Membrane Disease (RDS)
B06 ( ) Aspiration pneumonia
B07 ( ) Other pneumonia
B08 ( ) Recurrent apnea
B09 ( ) Bilirubin ≥ 20 mg/dl
B10 ( ) Other serious neonatal infection
B11 ( ) Persistent fetal circulation
B12 ( ) Neural tube defect
B13 ( ) Other major birth defect or syndrome

15. Code C. IDENTIFIED POST-DISCHARGE CONDITIONS
(Completed by private provider or local health department)

Birthweight 0 - 4 lbs. 8 oz. (0 - 2000 gms.):

C1a ( ) 0 - 1500 gms.
C1b ( ) 1501 - 2000 gms.

C02 ( ) Intracranial hemorrhage
C03 ( ) Meningitis
C04 ( ) Seizures
C05 ( ) Neurological abnormality due to perinatal asphyxia

Serious Environmental, Social, or Parenting Disturbance:

C6a ( ) Single parent with problem of family support
C6b ( ) Parent with incapacitating medical/mental handicap
C6c ( ) Parent with history of alcohol or drug abuse
C6d ( ) Mother demonstrates difficulty in maternal/infant interaction
C6e ( ) No prenatal care (drop-in)
C6f ( ) Inability to cope with stress

C07 ( ) Mother 14 years or less
C08 ( ) Developmental delay
C09 ( ) Vision impairment
C10 ( ) Hearing impairment
C11 ( ) Failure to thrive
C12 ( ) Gestational age 34 weeks or less
C13 ( ) Hyaline Membrane Disease (RDS)
C14 ( ) Aspiration pneumonia
C15 ( ) Other pneumonia
C16 ( ) Recurrent apnea
C17 ( ) History of bilirubin ≥ 20 gm/dl in nursery
C18 ( ) Other serious infections in infancy
C19 ( ) History of persistent fetal circulation
C20 ( ) Neural tube defect
C21 ( ) Other major birth defect or syndrome

16. I have reviewed above information & believe it to be correct

(Attending M.D's Signature) (Date)

17. Permission: I have had the "High Priority Infant Program" explained to me orally and in writing and agree to having my baby enrolled. I understand that enrolling my infant in this program requires sending certain personal and medical information, contained in our hospital records, to my primary medical provider, the health department in the county where my infant was born, and the county health department where I live. I understand I can withdraw my infant from this program at any time. My child's primary medical provider is

(Name) (Address)

(Witness Signature) (Date) (Parent's Signature)

18. Person Completing Form: Date:

DHS 2682 (Rev. 7-83)
MCH Branch (Review 7-84)

Original-Bosp. of Birth. Copy 1-Primary Med. Provider. Copy 2-Co. Hlth. Dept. of Residence

INSTRUCTIONS

PURPOSE: To identify and enroll infants at risk for developmental delay in the High Priority Infant Program.

PREPARATION: A record is completed for each infant who meets at least one of the high priority conditions as soon as possible after the condition(s) are identified. The identification record should be completed by hospital personnel and/or local health department staff. High Priority identification records for infants transferred to other hospitals should be completed by the staff of the hospital to which the infant is transferred.

DISTRIBUTION:
(1) Original - retained by hospital where infant was identified.
(2) Copies 1 and 2 - hospital forwards to local health department.
(3) For resident birth - health department forwards copy 1 to primary medical provider (private physician). Retains copy 2.
(4) For non-resident birth - health department forwards copies 1 and 2 to local health department where infant resides.
(5) Health department where patient resides performs step #3 above.

Specific Instructions: Instruction numbers correspond to item numbers on the identification record.

2. Patient Number: Enter Division of Health Services assigned check digit in first block. Leave blank if check digit has not been assigned by the Division of Health Services. Enter the patient's nine digit social security number, starting with the second block. Enter the patient's temporary identification number starting with the second block, when patient does not have a social security number. Temporary numbers are assigned locally based upon the following protocol: last name initial (maiden name if married), first name initial, birthdate and sex (1 for male or 2 for female) --- GL0801762. The Division of Health Services will assign a new check digit for a patient converting from a temporary identification number to a social security number.

8. Address: Enter street or route #, town, county, and zip code. When the address is outside the city, give some identifying information in order to locate home.

9. Telephone: Enter telephone number. When the family does not have a telephone, secure a telephone number where family may be reached.

12. Corrected Birthdate: Subtract actual gestational age (weeks) at birth by E.D.C. or Dubowitz from 40 weeks + actual birthdate = corrected birthdate, e.g., 40 weeks - 36 weeks (Dubowitz) = 4 weeks + actual birthdate 7-1-83 = corrected birthdate 7-29-83.

13. Code A. Identified Nursery Conditions: "X" appropriate conditions on Code A.

14. Code B. Identified Nursery Conditions: "X" appropriate conditions on Code B.

B1a. Single parent with problem of family support - Mother living alone and/or isolated from family or friends.

B1d. Mother demonstrates difficulty in maternal/infant interaction - A pattern of negative attitudes toward infant suggesting difficulty in bonding (development of positive relationship).

15. Code C. Identified Post-Discharged Conditions: "X" appropriate conditions in Code C. (Completed by private provider or local health department).

C6d. Mother demonstrates difficulty in maternal/infant interaction: A pattern of negative attitudes toward infant suggesting difficulty in bonding (development of positive relationship).

C6f. Inability to cope with stress: A history of parent(s)' inability to adapt to stressful circumstances caused by life crises, such as death, handicaps, and unemployment. Poor adaptation may be manifested through abusive behavior, alcoholism, depression, psychosis, and drug addiction.

C08. Developmental delay: A delay is a failure to master (achieve) a developmental skill by the age 90% of normal children would accomplish in the developmental areas of person-social skills, fine and gross motor skills, and language and communication skills.

C09. Visual impairment: Poor vision or blindness; or compromised development in a child because of equivocal visual performance.

C10. Hearing impairment: Partial hearing loss or deafness; or compromised development in a child because of equivocal auditory performance.

C11. Failure to thrive: A condition in which infants and children fail to grow at the expected rate. The clinical picture not only involves lack of weight gain and, in many cases, weight loss; but also there are usually signs of developmental retardation. Causes vary and can be organic or environmental in nature.

17. Permission: Enter name of Primary Medical Provider that the parent states will be delivering health care to the patient. Obtain signature of either parent, witness signature and enter date.

RETENTION: Destroy when infant-child reaches 28 years of age and has not received services within the last ten (10) years. (Reference: Records Disposition Schedule, Patient Clinical Records, 1982).

ORDER ADDITIONAL RECORDS FROM: Mailing Room, Division of Health Services P.O. Box 2091, Raleigh, NC, 27602-2091

Appendix 2

North Carolina Department of Human Resources
Division of Health Services

HIGH PRIORITY INFANT TRACKI:

1. Child's Last Name First Name MI

2. Patient Number:
Check digit - - -

3. Date of Birth: Month Day Year

4. Corrected Birth Date: Month Day Year

5. Date of Tracking: Month Day Year

6. Tracking Interval: (*Mark only one*)
- ☐ 3-4 months
- ☐ 6-7 months
- ☐ 12-13 months

7. Mother's Last Name First Name MI

8. Tracking Data:
Child Under your Care: ☐ Yes ☐ No
Reason Why Not Under Care:
Moved ☐ Refused Service ☐
Lost to Follow-up ☐ Died ☐

9. Visit to Family by Public Health Nurse Requested:[14] ☐ Yes ☐ No
Reason for Request: _____

10. Tests Results:

	Normal	Questionable	Abnormal
Denver Prescreening Developmental Questionnaire	☐	☐	☐
Denver Developmental Screening Test	☐	☐	☐

11. Child Referred to:
Developmental Evaluation Program ☐ Yes ☐ No
PACT, ECIS and Other Intervention Programs ☐ Yes ☐ No

12. Signature: Date:

13. *Return original and copy 1 to Local Health Department:*
Name: *Address:* *Telephone:*

14. Results of Public Health Nurse's Visit:

15. Public Health Nurse's Signature: Date

DHS 2683 (Rev. 7-83)
MCH Branch (Review 7-84)

Original and Copy 1 - Primary Medical Provider
Copy 2 - County Health Department of Residence

INSTRUCTIONS

PURPOSE: To track infants enrolled in the High Priority Infant Program and assist in the accumulation of relevant information concerning care received by these infants.

PREPARATION: The local health department in the county where the infant resides will initiate the tracking record on each high priority infant at 3-4 months, 6-7 months and 12-13 months of age. Tracking data may be obtained from the Primary Medical Provider by mail or telephone.

DISTRIBUTION: (1) Health department forwards original and copy 1 to primary medical provider. Retains copy 2.

(2) Primary medical provider completes items 8-12 and returns original and copy 1 to local health department.

(3) After home visit is made, local health department completes item 14 and returns original to primary medical provider.

Specific Instructions: Instruction numbers correspond to item numbers on the tracking record.

2. Patient Number: Enter Division of Health Services assigned check digit in first block. Leave blank if check digit has not been assigned by the Division of Health Services. Enter the patient's nine digit social security number, starting with the second block. Enter the patient's temporary identification number, starting with the second block, when patient does not have a social security number. Temporary numbers are assigned locally based upon the following protocol: last name initial (maiden name if married), first name initial, birthdate and sex (1 for male or 2 for female) --- GL0801762. The Division of Health Services will assign a new check digit for a patient converting from a temporary identification number to a social security number.

8-11. To be completed by Primary Medical Provider and returned to local health department requesting information.

8. Tracking Data:

Child Under Your Care: "X" appropriate block. A child is under care when the child is receiving regular preventive child health supervision.

Reason Why Not Under Care: "X" appropriate item, e.g., moved [X] .

9. Visit to Family by Public Health Nurse Requested: "X" appropriate block.

Reason for Request: State purpose for visit, e.g., assist mother in feeding techniques of infant with cleft palate.

10. Test Results: "X" appropriate block indicating results of Denver Pre-screening Developmental Questionnaire and the Denver Developmental Screening Test. Leave blank if above have not been done.

11. Child Referred to: "X" appropriate block if the infant was referred to Developmental Evaluation Program, PACT, ECIS, and other Intervention Program.

12. Signature: The person who enters data 8-11 will sign.

13. Completed by High Priority Infant Contact Nurse: Enter name of Public Health Nurse, Address of Local Health Department, and Telephone of Local Health Department.

14. Results of Public Health Nurse's Visit: Local Health Department may attach copy of nursing notes pertaining to home visit.

RETENTION: Destroy when infant-child reaches 28 years of age and has not received services within the last ten (10) years. (Reference: Records Disposition Schedule, Patient Clinical Records, 1982)

ORDER ADDITIONAL RECORDS FROM: Mailing Room, Division of Health Services, P.O. Box 2091, Raleigh, N.C. 27602-2091

Appendix 3

HOSPITAL CODES FOR ITEM #12

PATIENT DATA RECORD DHS 3108 (7/83)

COUNTY	HOSPITAL	CODE
Out of Hospital	Not Applicable	00H
Out of State	Not Applicable	00S
ALAMANCE		
Burlington	Alamance Co. Hospital	01N
Burlington	Mem. Hosp. of Alamance County	010
ALEXANDER		
Taylorsville	Alexander Co. Hospital	02B
ALLEGHANY		
Sparta	Alleghany Co. Memorial Hosp.	03B
ANSON		
Wadesboro	Anson County Hospital	04I
ASHE		
Jefferson	Ashe Memorial Hospital	05I
AVERY		
Banner Elk	Charles A. Cannon, Jr. Memorial Hospital	06N
Crossnore	Garrett Mem. Hospital	06C
BEAUFORT		
Washington	Beaufort Co. Hospital	07N
Belhaven	Pungo District Hospital	07B
BERTIE		
Windsor	Bertie Co. Memorial Hospital	08I
BLADEN		
Elizabethtown	Bladen County Hospital	09I
BRUNSWICK		
Supply	Brunswick County Hospital	10N
Southport	J. Arthur Dosher Mem. Hospital	10F
BUNCOMBE		
Asheville	Mem. Mission Hosp. of Western NC	11N
BURKE		
Morganton	Grace Hospital	12N
Valdese	Valdese General Hospital	12I
CABARRUS		
Concord	Cabarrus Memorial Hospital	13N
CALDWELL		
Lenoir	Caldwell Memorial Hospital	14N
CARTERET		
Sea Level	Sea Level Hospital	16B
Morehead City	Carteret Co. General Hosp.	16N
CATAWBA		
Hickory	Catawba Memorial Hospital	18O
Hickory	Glenn R. Frye Mem. Hospital	18I
CHATHAM		
Siler City	Chatham Hospital	19I
CHEROKEE		
Andrews	Dist. Memorial Hospital of Southwestern N.C.	20C
Murphy	Murphy Medical Center	20N
CHOWAN		
Edenton	Chowan Hospital	21F
CLEVELAND		
Shelby	Cleveland Memorial Hospital	23N
Kings Mountain	Kings Mountain Hospital	23I
Boilings Springs	Crawley Memorial Hospital	23C
COLUMBUS		
Whiteville	Columbus County Hospital	24I
CRAVEN		
Cherry Point	Naval Hospital	25I
New Bern	Craven County Hospital	25K
CUMBERLAND		
Fayetteville	Cape Fear Valley Hosp.	26Q
Fort Bragg	Womack Army Hospital	26P
DAVIDSON		
Thomasville	Community Gen. Hospital of Thomasville	29J
Lexington	Lexington Mem. Hospital	29I
DAVIE		
Mocksville	Davie County Hospital	30B
DUPLIN		
Kenansville	Duplin General Hospital	31F
DURHAM		
Durham	Duke University Medical Center	32N
Durham	Durham Co. General Hospital	32P
EDGECOMBE		
Tarboro	Edgecombe General Hospital	33I
FORSYTH		
Winston-Salem	Forsyth Memorial Hospital	34Q
Winston-Salem	North Carolina Baptist Hosp.	34P
FRANKLIN		
Louisburg	Franklin Memorial Hospital	35I
GASTON		
Gastonia	Gaston Memorial Hospital	36N
GRANVILLE		
Oxford	Granville Hospital	39I
GUILFORD		
High Point	High Point Memorial Hosp.	41O
Greensboro	L. Richardson Mem. Hosp.	41I
Greensboro	Moses H. Cone Mem. Hosp.	41N
Greensboro	Wesley Long Comm. Hospital	41L
HALIFAX		
Scotland Neck	Our Community Hospital	42B
Roanoke Rapids	Halifax Memorial Hosp.	42O
HARNETT		
Dunn	Betsy Johnson Mem. Hospital	43I
Erwin	Good Hope Hospital	43N
HAYWOOD		
Clyde	Haywood County Hospital	44N
HENDERSON		
Bat Cave	Valley Clinic and Hospital	45C
Hendersonville	Margaret R. Pardee Mem. Hosp.	45J
Fletcher	Fletcher Hosp. and Medical Ctr.	45I
HERTFORD		
Ahoskie	Roanoke-Chowan Hospital	46I
IREDELL		
Statesville	Davis Hospital	49N
Statesville	Iredell Memorial Hospital	49O
Mooresville	Lowrance Hospital	49P
JACKSON		
Sylva	C. J. Harris Comm. Hospital	50F

COUNTY	HOSPITAL	CODE
JOHNSTON		
Smithfield	Johnston Memorial Hospital	51N
LEE		
Sanford	Central Carolina Hospital	53I
LENOIR		
Kinston	Lenoir Memorial Hospital	54N
LINCOLN		
Lincolnton	Gordon Crowell Mem. Hosp.	55N
Lincolnton	Lincoln Co. Hospital	55O
MACON		
Franklin	Angel Community Hospital	56I
Highlands	Highlands-Cashiers Hospital	56C
MARTIN		
Williamston	Martin General Hospital Unit	58G
Robersonville	Robersonville Community Hosp.	58C
McDOWELL		
Marion	Marion Gen. Hospital	59I
MECKLINBURG		
Charlotte	Charlotte Memorial Hospital	60N
Charlotte	Presbyterian Hospital	60Q
MITCHELL		
Spruce Pine	Spruce Pine Comm. Hospital	61F
MONTGOMERY		
Troy	Montgomery Mem. Hospital	62I
MOORE		
Pinehurst	Moore Memorial Hospital	63N
NASH		
Rocky Mount	Nash General Hospital	64Q
Rocky Mount	Rocky Mount Sanitarium	64K
NEW HANOVER		
Wilmington	Cape Fear Mem. Hospital	65I
Wilmington	New Hanover Mem. Hospital	65P
ONSLOW		
Jacksonville	Naval Regional Medical Center	67N
Jacksonville	Onslow Memorial Hospital	67I
ORANGE		
Chapel Hill	N.C. Memorial Hospital	68N
PASQUOTANK		
Elizabeth City	Albemarle Hospital	70I
PENDER		
Burgaw	Pender Memorial Hospital	71B
PERSON		
Roxboro	Person County Memorial Hosp.	73I
PITT		
Greenville	Pitt County Memorial Hosp.	74N
POLK		
Columbus	St. Luke's Hospital	75G
RANDOLPH		
Asheboro	Randolph Hospital	76N
RICHMOND		
Hamlet	Hamlet Hospital	77I
Rockingham	Richmond Mem. Hospital	77J
ROBESON		
Lumberton	Southeastern General Hosp.	78O

COUNTY	HOSPITAL	CODE
ROCKINGHAM		
Reidsville	Annie Penn Memorial Hosp.	79J
Eden	Morehead Memorial Hospital	79I
ROWAN		
Salisbury	Rowan Memorial Hospital	80N
RUTHERFORD		
Rutherfordton	Rutherford Hospital	81N
SAMPSON		
Clinton	Sampson County Memorial Hosp.	82N
SCOTLAND		
Laurinburg	Scotland Memorial Hospital	83N
STANLY		
Albemarle	Stanly County Hospital	84N
STOKES		
Danbury	Stokes-Reynolds Memorial Hosp.	85I
SURRY		
Elkin	Hugh Chatham Memorial Hospital	86I
Mt. Airy	Northern Hosp. of Surry County	86N
SWAIN		
Bryson City	Swain County Hospital	87B
Cherokee	U.S. Public Health Service Hosp.	87C
TRANSYLVANIA		
Brevard	Transylvania Community Hospital	88F
UNION		
Monroe	Union Memorial Hospital	90N
VANCE		
Henderson	Maria Parham Hospital	91I
WAKE		
Raleigh	Rex Hospital	92N
Raleigh	Wake County Medical Center	92O
WARREN		
Warrenton	Warren General Hospital	93F
WASHINGTON		
Plymouth	Washington County Hospital	94B
WATAUGA		
Blowing Rock	Blowing Rock Hospital	95B
Boone	Watauga County Hospital	95F
WAYNE		
Goldsboro	U.S. Air Force Hospital	96I
Goldsboro	Wayne County Memorial Hosp.	96N
Grantham	Grantham Medical Clinic	96S
WILKES		
N. Wilkesboro	Wilkes General Hospital	97N
WILSON		
Wilson	Wilson Memorial Hospital	98N
YADKIN		
Yadkinville	Lula C. Boots Memorial Hosp.	99F

HOME VISIT WORKSHEET

N. C. DEPARTMENT OF HUMAN RESOURCES

DIVISION OF HEALTH SERVICES

Child's Name, Sex, Race, D.O.B., #

Mother's Name:_____ Mother's Date of Birth:_____

Father's Name:_____ Father's Date of Birth:_____

INTRODUCTION NURSE MAY USE: "You may have been aware that there were some medical concerns about your baby while he/she was in the hospital. At the health department, we feel it is important to offer some special attention to babies like yours during the first months of life to assure a good beginning for both parents and child. In order to know the best way to offer help and to keep some common information of these babies and their families, we need to get some information from you."

PART I: SOCIOECONOMIC/ENVIRONMENTAL DATA

	2w	3m	6m	9m
1.A. How many people live in the house with the baby?				
B. Who are they:				
Mother				
Father				
Brothers and sisters				
Grandparents				
Other relatives				
Non-related adults				
Non-related children				
2.A. How many rooms, not counting bathrooms, are in the house?				
B. How many bedrooms?				
C. How long have you lived here?				
3. Do you currently have:				
Television				
Radio				
Indoor plumbing				
Working refrigerator				
Working stove				
Telephone				
Washer				
Clothes Dryer				
4.A. Do you have a car/truck in working order?				
B. If no, how do you get around? (specify)				
5.A. How many grades did you finish in school?				
B. How many grades did the father finish in school?				
6.A. Do you have a job outside the home?				
B. If yes, where?				
Income? a) less than $5,000, b) $5,000-9,999, c) $10,000-14,999, d) $15,000-19,999, e) $20,000-40,000, f) more than $40,000				
C. If no, do you plan to go to work?				
To school?				
When?				
7. If yes in #6, who looks after (or will look after) your child while you work or go to school?				

DHS 3122 (7/83)
MCH Branch (Review 8/84)

	2w	3m	6m	9m
DATE:				
SIGNATURE:				

8.A. Does the father work outside the home?
B. If yes, where?
C. Income? a) less than $5,000, b) $5,000-9,999 c) $10,000-14,999, d) $15,000-19,999, e) $20,000-40,000, f) more than $40,000
D. If parents are separated, does the father contribute to the child's support?

COMMENTS OR OBSERVATIONS: _____

_____

_____

_____

PART II: HEALTH CARE INFORMATION

INTRODUCTION NURSE MAY USE: "I would like to find out more about your baby, how he/she is doing and of any concerns you may have about him/her."

	2w	-3m	6m	9m
DATE:				
SIGNATURE:				

1. Were you told there were some health concerns about your baby when he/she was born?
2. Do you understand why the doctor was concerned about your baby?
3. Do you have questions about your doctor's concerns?
4. Do you have concerns about your baby?
5. Have you thought about what may have caused your baby baby's condition?
6.A. Was your baby given special medication or treatments?
B. Is he/she still on medication or treatments?
C. How often is medication or treatment given?
D. Is it hard to get the baby to take it?
7.A. Do you have other children with medical/learning problems?
B. If yes, who?
C. Source of care?

COMMENTS OR OBSERVATIONS: _____

_____

_____

_____

PART III: CAREGIVING/PATIENT-CHILD INTERACTION/STIMULATION

INTRODUCTION NURSE MAY USE: "For the first several months when a new baby comes home, the mother and baby are getting to know each other. It's a time of discovery for mothers. I'd like to talk with you about the discoveries you have made about your baby."

	2w	3m	6m	9m

1. Most of the time do you feel that your baby:
a. is smiling and pleasant
b. prefers to be alone
c. responds readily to affection
d. gets angry when he/she doesn't have his/her way
e. is often cranky
f. doesn't obey or listen
2. Have you had to punish your baby?
3. If so, what kind of punishment works best for you?
4. How often do you have to punish him/her a week?
5.A. Does your baby eat well?
B. If there are problems, how do you get him/her to eat?

	2w	3m	6m	9m
6.A. Does your baby cry much?				
B. Can you get him to stop easily?				
7.A. Has he/she had trouble sleeping?				
B. If so, what do you do?				
8. Who takes care of the baby most of the time?				
9. Are you having trouble getting your work done while the baby is awake?				
10.A. Do you find time to play with your baby during the day?				
B. How much time each week?				
11.A. Are there others who like to spend time with your baby?				
B. Who?				
C. How much time a week?				
12. Are there any children who play with him/her?				
13.A. Does anyone take your baby out of the house?				
B. How often?				
C. Where to?				
14. Please show me your baby's favorite toy. (name toy)				
DATE:				
SIGNATURE:				

COMMENTS OR OBSERVATIONS: _____

_____

_____

_____

PART IV: FAMILY ADJUSTMENT

INTRODUCTION NURSE MAY USE: "Having a baby requires big adjustments for a family. I'd like to talk with you about how the adjustment has been for your family and for you."

	2w	3m	6m	9m
1. Since your baby was born have you or your husband/ companion had:				
a. any marked change in appetite?				
b. difficulties sleeping?				
c. changes in activity level (feeling tired and worn out)?				
d. feelings of sadness?				
2. Do you think you get out and away from the children enough?				
3.A. Do you plan to have more children?				
B. Are you on any birth control method?				
4.A. Does someone help you take care of the children?				
B. Who?				
5. Does someone help you around the house?				
6. Do you feel you get enough help?				
7. Do you have neighbors or relatives close by who you visit and who visits you?				
8.A. Are you in any groups or organizations such as church or clubs?				
B. What?				
9.A. If you get worried or upset, do you have someone to talk to about your concerns?				
B. Who?				
10.A. Is there something you would like to change about your current situation?				
B. What?				
DATE:				
SIGNATURE:				

COMMENTS OR OBSERVATIONS: _____

PART V: HEALTH CARE RESOURCES/COMMUNITY AGENCIES SUPPORT

INTRODUCTION NURSE MAY USE: "You know it is important that your baby has regular medical care. I would like to check where your baby is going."

	2w	3m	6m	9m
1.A. When your baby needs ordinary health care (like baby shots), where do you go?				
B. When did you last go?				
C. When is your next appointment?				
2.A. When your baby is sick, where do you go?				
B. When did you last go?				
3.A. Are there any agencies working with you, your baby or other members of your family?				
B. Who?				
DATE:				
SIGNATURE:				

COMMENTS OR OBSERVATIONS: _____

INSTRUCTIONS FOR COMPLETING HOME VISIT WORKSHEETS

GENERAL INFORMATION:

At 9 months (corrected by birthdate) or when the infant is referred to the DEC or NICU Follow-up Clinic, a summary note of each section is forwarded with other pertinent information.

A summary of the home visit will be forwarded to the infant's local provider after each visit.

SPECIFIC INFORMATION:

1. Part I: This section will be assessed at the two-week visit and updated at subsequent visits.
2. Part II: This section will be assessed at the two-week visit and updated at subsequent visits.
3. Part III: This section will be assessed in depth at each visit.
4. Part IV: This section will be assessed in depth at each visit.
5. Part V: This section will be assessed at the two-week visit and updated at subsequent visits.
6. Comments or Observation: At the end of each section is an area that may be utilized to document any information gathered that pertains to that section.
7. The Worksheets, if used, may become a part of the infant's record.

RETENTION: If retained in patient record, retain until individual reaches 28 years of age and has not received services within the last 10 years. Otherwise discard after information is transferred to the patient's record and nine month summary sent to the DEC or NICU Follow-up Clinic.

ADDITIONAL FORMS: Mail Room, Division of Health Services, P.O. Box 2091, Raleigh, North Carolina, 27602.

Appendix 5

EVALUATION TOOL FOR HOME VISIT WORKSHEET

1. Do you use this tool for home visits? yes no

2. If yes, has the tool been helpful? yes no

3. Approximately how long does it take you to complete the form at:

   2 weeks _____
   3 months _____
   6 months _____
   9 months _____

4. Approximately how long does it take you to complete your summary note prior to the 9 month visit? _____

5. What has been most helpful for you? (please be specific)

6. What has been least helpful for you? (please be specific)

7. When the form is revised, what would you like to see changed:

   Format: _____

   _____

   _____

   _____

   Content: _____

   _____

   _____

   _____

PLEASE COMPLETE AND RETURN BY JULY 1, 1984 TO:

SISTER EDNA ENGLISH
NURSING CONSULTANT
EASTERN REGIONAL OFFICE
404 ST. ANDREWS DRIVE
GREENVILLE, N.C. 27834

Suggested High Priority Infant Tickler System

1. Set up series of twelve (12) folders marked January, February, March, etc. plus a Pending folder.

2. Upon receipt of record DHS 2682 (Rev. 7-1-83) from hospital, initiate three (3) records DHS 2683 (Rev. 7-1-83) indicating tracking dates and file in appropriate folders for 3, 6, and 12 months in advance.

3. If home visit worksheets, DHS 3122 (7-1-83) are used for home visiting, indicate appropriate dates for the 2 weeks, 3, 6, and 9 months visits on the first page of the home visit worksheets. (See Part I - Dates may be placed above specified intervals). File in appropriate monthly folder.

4. For PDQ and DDST use same procedure as in item 3.

5. On consistent schedule early each month, forward tracking record DHS 2683 original (pink) and copy 1 (white) to primary medical provider. Information may be obtained by telephone.

   (a) File Health Department copy 2 (green) in alphabetical order in Pending folder awaiting return of original (pink) and copy 1 (white).

   (b) Upon receipt of original and copy 1 remove copy 2 from Pending folder and destroy copy 2.

   (c) After home visit is made, Health Department completes item 14 and returns original to primary medical provider. Retains copy 1.

6. On consistent schedule early in the month, complete home visits, PDQs and DDSTs as indicated. Results of PDQs and DDSTs, summaries of home visits, and other documents should be sent to the Developmental Evaluation Center and/or other follow-up clinic prior to the 1 year developmental assessment.

DATES FOR TRACKING, HOME VISITING, PDQ, DDST, AND THE 1 YR. DEVELOPMENTAL ASSESSMENT ARE DETERMINED BY THE CORRECTED BIRTHDATES.

NORTH CAROLINA
CHAPTER
AMERICAN ACADEMY
OF PEDIATRICS
and the
NORTH CAROLINA
PEDIATRIC SOCIETY

P. O. Box 27167
Raleigh, NC 27611
(919) 833-3836

David T. Tayloe, MD
Chairman
George E. Prince, MD
Alternate Chairman
James B. Rouse, MD
Treasurer
Charles K. Scott, MD
Secretary

Appendix 7

INFANT TRACKING PROGRAM UPDATED

Dr. Robert Dillard reported to the Liaison Committee in Greensboro in January that the Infant Tracking Program is in the Process of being revised and updated. A task force has been working on reviewing the program to make it more efficient and pertinent. Fewer babies will be tracked and those will be followed more closely. They plan for closer communication with the physicians. The infants will be divided into three groups. Group A - very high risk infants - which will have mandated tracking on the basis of a home visit by a registered nurse at two weeks, three, six and nine months and Denver Developmental Screening Tests included. Also, one year developmental assessment will be done at a developmental evaluation center. About 1200-1500 infants per year will fall into this category. Group A will include: (1) birthweight of less than 1500 grams, (2) intracranial hemorage, (3) meningitis, (4) seizures, and (5) neurological abnormalities due to perinatal asphyxia. The local health department personnel will be contacting local doctors to see how much of the testing the doctors want the health department to do. There will be a Group B - maternal age below 15, birthweight below 2000 grams and gestational age below 34 weeks - and a Group C to include any other criteria in which a health care provider may request tracking.

We feel that the updating and improvement of this program will make it more efficient and will enable all persons to have a better chance to evaluate perinatal care in our state.

# # #

Appendix 8

North Carolina Hospital Association

POST OFFICE BOX 10937 112 COX AVENUE TELEPHONE 919-832-9550

RALEIGH, NORTH CAROLINA 27605

MEMORANDUM TO: Chief Executive Officers, Member Hospitals

FROM: W. E. Roye, Director of Management Services

DATE: April 15, 1983

SUBJECT: High Priority Infant Program

Since its inception in 1979, the High Priority Infant Program of the Department of Human Resources has performed a most valuable service in seeing that infants with potential developmental problems were identified early and received appropriate follow-up care. This program is continuing and will include a development assessment at one year of age. The program essentially covers three groups of infants. Group A are those born with serious medical problems, including birth weights of less than 1,500 grams. Group B are infants of mothers under 15 years of age and weighing less than 2,000 grams. Group C are those infants exhibiting developmental problems after hospital discharge, the majority of whom will be identified in physicians' offices and well baby clinics.

The Department of Human Resources in April will write to every pediatrician and family practitioner in the state, county health departments, and to all hospital nurseries encouraging everyone involved to be alert to any children that might need follow-up care. The early detection and treatment of many problems of young children is vital to both the child's developmental chances to say nothing of the parents unnecessary or prolonged anguish.

To be eligible for this program, the infant's parents and physicians must both consent. This memorandum is to encourage each involved hospital CEO to lend his support to this important program during any discussions of its merit this spring. Enclosed is some materials further describing this effort.

For more information call Ms. Laura Harbison or Dr. Jimmie Rhyne at 919/733-7791.

WER:ppp

Enclosures

Appendix 9

NORTH CAROLINA DEPARTMENT OF HUMAN RESOURCES
DIVISION OF HEALTH SERVICES

PATIENT DATA RECORD

7. Date of Visit/Report — Month | Day | Year

8. Service Site

9. Administrative Action *(complete DOB when changing Name or I.D. Number)*
☐ 1. Billing Only ☐ 2. Name Change ☐ 3. Birth Date Change
☐ 4. I.D. Number Change (Enter Old I.D. # Below)
H

1. Last Name | First Name | MI

2. Patient Number H

Enter once or for update

3. Date of Birth — Month | Day | 19 Year

4. Race (Mark One Only)
☐ White ☐ Black ☐ Am. Ind. ☐ Other

5. Sex ☐ Male ☐ Female

6. County of Residence *(Enter 999 for Migrants)*

10. Patient Type ☐ 1. New 2. Continuation

Service Type — Cl. Type
1. Child Health ☐ Screen ☐ Rx ☐ Limited Service
2. CC ☐ Assess ☐ Rx
3. Dental ☐

Prior Authorization No.

High Priority Infant Data

11. Risk Condition Code(s)

Hospital of Birth | Hospital Transfer to

12. Tracking Interval ☐ 1. 3 Mo. 2. 6 Mo. 3. 12 Mo.

Y = Yes; N = No; E = Expired

	2 Wk	1 Mo.	3 Mo.	6 Mo.	9 Mo.	12 Mo.
Home Visit (Y or N)						
PDQ/DDST (Y or N)						
Receiving Care (Y or N)						
Closed to Tracking (Y, N or E)						

13. Enter Dose Number(s) of Immunization(s) Provided this Visit

DTP/DT/Td (Adult) | OPV/IPV | MMR | MR | Measles | Rubella | Mumps

14. Diagnostic or Procedure Code(s) – *(Enter one type only)*
☐ 1. ADA 2. CPT 3. ICD-9 4. ICHPPC 5. SHDC

15. Medicaid Billing —

Casehead Name (EPSDT Only) _____
Last First

16 Provider(s) of Service This Visit *(Mark those seen)*

☐ Audiologist	☐ CNM/NP/PA	☐ CHA/CHT
☐ Dental Hyg.	☐ Dentist	☐ Genetic Spec.
☐ Hlth. Educ.	☐ Lab Staff	☐ Nurse
☐ Nutr. Staff	☐ OT/PT	☐ Pharmacist
☐ Physician	☐ Soc. Worker	☐ Sp/Lang Sp.

17. Medical and Laboratory Services

1. Height — Inches / 8 — or — Centimeters
2. Weight — Pounds | Ozs — or — Kilograms
3. Hemoglobin — Grams — or — Hct. Percent

	Service Provided	Referred to Other HD Service	Referred to Other Provider
4. History			
5. Physical Exam			
6. Dental Screen			
7. Blood Pressure			
8. Vision Screen			
9. Hearing Screen			
10. Dev. Screen			
11. Urinalysis			
12. Tuberculin			
13. Lead Level			
14. Sickle Cell			
15. Nutr. Assess			
16. Scoliosis Screen			
17. X-ray			
18. EEG/EKG			
19. Anti-convulsant Blood Level			

18. Suspected Developmental Problem(s) *(CC PROGRAM ONLY)*
☐ None ☐ Coordination ☐ Emot/Social
☐ Genetic ☐ Hearing ☐ Learning ☐ Sp/Lang.

19. Next EPSDT Screening Appointment — Month | Year

20. Local Use Code(s) *(Optional)*

DHS 3108 (3/84)
Maternal & Child Care (Review 1/85)

Mail Part 1 to MCC Data Unit. Retain Part 2 at service site.
Send Part 3 to local DSS if **EPSDT** visit; otherwise, destroy.

INSTRUCTIONS

PURPOSE: To collect data on the services provided and persons served through public health sponsored child health, crippled children's and dental health clinics and programs.

PREPARATION: Complete a PATIENT DATA RECORD for each patient visit. Only one service, e.g., child health, dental health or crippled children, may be recorded on a PATIENT DATA RECORD.

IMPRINTER CARD: Use of the imprinter card satisfies the requirements of Items 1-6.

Specific Instructions: Instruction numbers correspond to item numbers on the PATIENT DATA RECORD.

2. **Patient Number:** Enter the patient's nine digit social security number. Enter the patient's temporary identification number when the patient does not have a social security number. Temporary numbers are assigned locally based upon the following protocol:
   Block 1 = Last name initial (maiden name if married woman)
   Block 2 = First name initial
   Blocks 3 - 8 = Date of birth, e.g., May 1, 1984 = | 0 | 5 | 0 | 1 | 8 | 4 |
   Block 9 = Sex, e.g., 1 for male, 2 for female

   If a temporary identification number has already been assigned to another patient, please call the Data Unit, 919-733-2973, for assistance.

3. **Date of Birth:** Enter patient's eight digit date of birth, e.g., May 1, 1984 = | 0 | 5 | 0 | 1 | 1 | 9 | 8 | 4 | Estimate the age of patient and compute the approximate year of birth when the date of birth is unknown. Enter 07 for the month and 15 for the day. The birth date of medicaid recipient must agree with local Department of Social Services records in order to avoid denial of claim.

6. **County of Residence:** Enter the three digit county code where the patient resides. Refer to *Code Sheet One* in USER'S MANUAL for county codes.

7. **Date of Visit/Report:** Enter the six digit date of visit, e.g., May 1, 1984 = | 0 | 5 | 0 | 1 | 8 | 4 | If no patient visit took place, e.g., administrative action or high priority, enter the date this PATIENT DATA RECORD was completed.

8. **Service Site:** Enter the five character Division of Health Services assigned service site number where the patient received services this visit. If no patient visit took place, enter the service site code where the person completing the PATIENT DATA RECORD normally works. Refer to *Code Sheet Two* in USER'S MANUAL for service site codes.

9. **Administrative Action:**
   1. **Billing Only:**
      Resubmitting Denied Claims: Make necessary corrections on local copy. Enter "1". Make photocopy and resubmit to Data Unit.
      Billing After Submission of Original Data Record: Enter "1" Complete Item 15 on local copy. Make photocopy and submit to Data Unit.
   2 & 3 **Name Change/Birth Date Change:** Enter "2" or "3" when correcting a patient's name or birth date respectively. Enter patient's birth date, Item 3, when making a change.
   4 **I.D. Number Change:** Enter "4" when replacing a patient's temporary identification number with the social security number or when making corrections. Enter the patient's old I.D. number in Item 9 and the birth date in Item 3 when making an identification number change.

10. **Patient Type:** Enter the appropriate patient type code. Enter "1" for a patient **new** to this service; "2" for a **continuation** patient making a return visit for this service. A patient may be "new" to each service only one time.
    Service Type: Enter "X" in the block indicating the service provided this visit. For Crippled Children's, also enter the two digit clinic code, e.g., 22 for orthopedic. Refer to USER'S MANUAL for service definitions and Crippled Children's clinic codes.

11. **Risk Condition Code(s):** Enter the three character risk condition code(s) of the infant being reported. Also enter the three character hospital code where the infant was born and the hospital code where the infant was transferred to if applicable. Item 11 should be completed at the three-month tracking interval by the county responsible for tracking. Refer to *Code Sheets Three and Four* in USER'S MANUAL for risk condition and hospital codes.

12. **Tracking Interval:** Enter the appropriate code to indicate tracking interval as determined by corrected birth date, e.g., "1" - 3 months; "2" - 6 months; and "3" - 12 months. Complete **all** blocks for appropriate tracking interval. Enter "Y" for yes or "N" for no to indicate whether or not home visit was made, PDQ/DDST was provided, and infant is receiving care. Enter "Y" for yes, "N" for no, or "E" for expired to indicate infant was closed to tracking.

14. **Diagnostic or Procedure Code(s):** Enter appropriate code type, i.e., "1" = ADA; "2" = CPT; "3" = ICD-9; "4" = ICHPPC; "5" = SHDC. Always enter code starting at far left, e.g., | 0 | 0 | 9 | 1 | . Refer to *Code Sheets Five, Six, Seven and Eight* in USER'S MANUAL for ADA, ICD-9, ICHPPC, and SHDC codes.

17. **Medical and Laboratory Services:** "X" only those medical and/or laboratory services provided. Also "X" those patient referrals resulting from medical and laboratory findings.

DISTRIBUTION: Attach one Batch Transmittal Sheet, DHS 3112, to each batch of 75 or less PATIENT DATA RECORDS. Mail Part 1 of the record to: **Maternal & Child Care Data Unit, N. C. Division of Health Services, P. O. Box 2091, Raleigh, N. C. 27602-2091.** Retain Part 2 at service site. Send Part 3 to local Department of Social Services if EPSDT visit; otherwise destroy.

DISPOSITION: This form may be destroyed in accordance with the Budget and Fiscal Records Standard and Programs Operational Records Standard of the RECORDS DISPOSITION SCHEDULE published by the Division of Archives and History.

REORDER INFORMATION: Additional copies of the record may be ordered on the Batch Transmittal Sheet, DHS 3112 from: Maternal & Child Care Data Unit, N. C. Division of Health Services, P. O. Box 2091, Raleigh, N. C. 27602 2091.

NORTH CAROLINA DEPARTMENT OF HUMAN RESOURCES
DIVISION OF HEALTH SERVICES

BATCH TRANSMITTAL SHEET/ORDER FORM

_____
Provider Name and Address

Batch No. | | | | | |

Service Site | | | | | |

Number of Records Submitted | | | |

Date | | | | | | |
Month | Day | Year

Batch Submitted By _____
Signature

1. Separate (i.e., batch) forms by type of service/activity as follows:
   Types of Service: *Child Health* *Dental Health* *Family Planning* *Pregnancy Outcome*
   Crippled Children *High Priority Infant Tracking* *Maternal Health* *Activity Record*
   Attach Part 1 of Batch Transmittal Sheet to each batch of forms before mailing to Maternal and Child Care Data Unit.
   Attach Part 2 of Batch Transmittal Sheet to each local copies of forms.
2. Batch No.: Enter appropriate code as listed below in Blocks 1 and 2, e.g., [C][H][ ][ ][ ], to indicate service/activity to be keypunched:
   CH = Child Health *DH = Dental Health* *FP = Family Planning* *PO = Pregnancy Outcome*
   CC = Crippled Children *HP = High Priority Infant Tracking* *MH = Maternal Health* *AR = Activity Record*
   Enter numeric digits in Blocks 3, 4, 5, e.g., [ ][ ][0][0][1], to indicate batch number. For example, the first batch of Child Health forms should be entered as [C][H][0][0][1]. At the beginning of each fiscal year, you may start numbering with 001 again.
3. Service Site: Enter the five digit service site code where the forms were completed or batched. Refer to *Code Sheet Two.*
4. Number of Records Submitted: Enter number of records contained in the batch. The maxium number of forms that can be attached to a Batch Transmittal Sheet is 999.
5. Date: Enter date that the batch of forms are submitted.

Mail To: MCC Data Unit
Division of Health Services
P.O. Box 2091
Raleigh, NC 27602-2091

ORDER FORM

DHS 3108 Patient Data Record _____
DHS 3109 Maternal Health-Family Planning Patient Data Record _____
DHS 3110 Pregnancy Outcome _____
DHS 3111 Activity Record _____
DHS 3112 Batch Transmittal Sheet and Order Form _____

Texas

THE TEXAS EARLY CHILDHOOD INTERVENTION PROGRAM

The Texas Early Childhood Intervention Program is a comprehensive, statewide program designed to serve all children from birth to age six who are handicapped, developmentally delayed, or at risk for developmental delay through identification, follow-up, intervention and indirect services. The legislation establishing the program mandated that four state agencies—the Department of Health, the Department of Mental Health and Mental Retardation, the Department of Human Resources, and the Education Agency—along with a representative from the public work together in a coordinated and cooperative manner to carry out the intent of the legislation.

The attached Early Childhood Intervention Tracking System forms were designed for collecting data about children who are receiving services from ECI funded programs. These forms and the collection protocol are currently under review and may be revised.

ESC-ID#

Date Referral Received

Referral Taken By

EARLY CHILDHOOD INTERVENTION TRACKING SYSTEM

Referral Form

Name of Child

Birthdate M F Sex Ethnicity

Parents

Street Address

City Zip County

(Area Code) Telephone Number

Current Status - F S A O
(Circle One)

Parent has been notified_____Yes_____No

Child's Home Language _____

Referring Agent

Title/Affiliation/Relationship to Student

Street Address

City Zip

(Area Code) Telephone Number

County

Services Request: Check appropriate blank(s)

___Intervention Program
___Screening
___Evaluation-Developmental
___Evaluation-Medical
___Parent Training
___Parent Counseling
___Case Management
___Respite Care
___Genetic Counseling
___Nutritional Services
___Educational Services
___Occupational Therapy
___Physical Therapy
___Speech and Language Therapy
___Adaptive Equipment
___Transportation
___Other

Comments/Additional Information:

Refer for Services:

Agency	Date	Results

FILMED FROM
BEST COPY AVAILABLE

Form Type: __

Date: __ Mo. __ Day __ Year

EARLY CHILDHOOD INTERVENTION CLIENT FORM

PROGRAM NAME: _____

CLIENT NAME: _____

PROGRAM ID: _ _ _ - _ _ _ _ _ _ _ _ _

CLIENT ID: _ _ _ _ _ _ _ _ _ _

Form Completed By: _____

1. Client's County of Residence: _____ _ _ _

2. Birthdate ..... __ Mo. __ Day __ Year

3. Birthweight ..... __ lbs. __ ozs.

or

__ __ gms. __

4. Apgar Score (at Five Minutes): ..... __ __

5. Date of Entry Into Program: ..... __ Mo. __ Day __ Year

6. Developmental Age at Entry: ..... __ Years __ Mo.

7. Current Developmental Age ..... __ Years __ Mo.

8. Time Client Spent on Waiting List Before Services Were Provided ..... __ Days

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9. Does Client Have a Congenital Problem?

Yes 1
No 2

9A. If YES, Please Check the Appropriate Problem:

1. Cerebral Palsy ___
2. Cleft Lip and Cleft Palate ___
3. Club Foot ___
4. Cystic Fibrosis ___
5. Congenital Dislocation of Hip ___
6. Congenital Heart Defects ___
7. Down's Syndrome ___
8. Epilepsy ___
9. Hearing Loss ___
10. Hemophilia ___
11. Hydrocephalus ___
12. Sickle Cell Anemia ___
13. Spina Bifida ___
14. Other _____ ___
Specify

10. Please Check the Categories of Impairment Below Which Apply to the Client:

1. At Risk ___
2. Developmentally Delayed Only ___
3. Blind/Visually Impaired ___
4. Deaf/Hearing Impaired ___
5. Deaf/Blind ___
6. Orthopedically Impaired ___
7. Other Health Impaired ___
8. Mentally Retarded ___
9. Emotionally Disturbed ___
10. Autistic ___
11. Learning Disabled ___
12. Multiply Handicapped ___
13. Other _____ ___
Specify

11. Is the Client Currently Receiving:

	Yes	No
Educational Instruction	[ ]	[ ]
Medical Services	[ ]	[ ]
Speech Therapy	[ ]	[ ]
Hearing Therapy	[ ]	[ ]
Physical Therapy	[ ]	[ ]
Occupational Therapy	[ ]	[ ]
Transportation	[ ]	[ ]
Parent Training	[ ]	[ ]
Parent Counseling	[ ]	[ ]
Diagnostic Evaluation - Medical	[ ]	[ ]
Diagnostic Evaluation - Social	[ ]	[ ]
Diagnostic Evaluation - Educational	[ ]	[ ]

12. Are Services Related to Client Provided at:

Home 1
Center 2
Combination 3

13. Are Services Provided Primarily to:

Parents 1
Child 2
Combination of Both 3

14. Are Services Provided Primarily to the Child by:

Professional Staff 1
Paraprofessional Staff 2
Parents 3
Other _____ 4
Specify

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15. Does Child Live With:

Mother Only	1
Father Only	2
Both Parents	3
Other Relatives	4
Other _____ (Specify)	5

16. Mother's Age: ..... __ __

17. Father's Age: ..... __ __

18. Annual Income of Family ..... $ __ __ __ __ __

19. Educational Level of Parents:

	Mother (Circle One)	Father (Circle One)
Less Than High School Graduate	1	1
High School Graduate	2	2
Some College	3	3
College Graduate	4	4
Graduate Degree	5	5

20. Developmental Disabilities in Family: (Check All That Apply)

	Yes	No
Blind/Visual Impairment	[ ]	[ ]
Deaf/Hearing Impairment	[ ]	[ ]
Deaf/Blind	[ ]	[ ]
Speech Impairment	[ ]	[ ]
Mental Retardation	[ ]	[ ]
Orthopedic Impairment	[ ]	[ ]
Emotionally Disturbed	[ ]	[ ]
Other _____ (Specify)	[ ]	[ ]

21. Number of Siblings: .....

22. Number of Siblings With Developmental Problems .....

23. The Parents:

		Yes	No
1.	Recognize Developmental Milestones	[ ]	[ ]
2.	Obtain Community Services Needed by Family	[ ]	[ ]
3.	Know How to Provide Adequate Nutrition and Health Supervision	[ ]	[ ]
4.	Participate on the Planning and Implementation of Appropriate Care Activities	[ ]	[ ]
5.	Understand Developmental Delay and the Special Needs Resulting From it	[ ]	[ ]
6.	Are aware of Their Feelings to Child and to Handicap	[ ]	[ ]

Utah

UTAH REGISTRY FOR HANDICAPPED PERSONS

The Utah Registry for Handicapped Persons of the Interagency Management Information System for the Handicapped (IMISH) is a computer assisted information system. It is not in and of itself a tracking system, but it can be used by those developing or operating a tracking system to facilitate the centralization of information.

Background

One of the findings of the Handicapped Child Data Project of the Utah Department of Health was that a central, multi-agency information management system would be one of the most effective tools used to eliminate gaps in services to handicapped people, track and help guide them through a confusing and sometimes conflicting system of services, and coordinate a multitude of agencies which often provide duplicate services. In addition, such a system could help plan future service, define true and accurate incidence rates, and provide invaluable information for other research efforts, sometimes tying into other registries, such as birth, death, genetics, geneology and birth defects. The Central Registry for Handicapped Persons is an ambitious project that has taken years to develop thus far, and will take years more to fully implement.

The Registry potentially can be used for a multitude of purposes, including child find, case management tracking, planning, justifying services, program evaluation and other research.

First, the Registry will include the names, diagnoses, services provided, dates and places of services and contacts or resource people for handicapped persons served by the Utah Department of Social Services, the Utah Office of Education and Board of Education, and the Utah Department of Health. The ultimate goal is for the Registry to include all handicapped individuals provided service by either public or private agencies in Utah. All age groups from birth to death will be covered. Eventually, the system will be totally interactive with frequent oversight reviews and continuous updating of information.

Accountability

Protection of the rights of confidentiality of those individuals on the Registry has been and is a major concern of this project. The legal and practical considerations of this problem have been worked out extensively and a brief summary of this issue would not do it justice. Suffice it to say that clearly defined procedures have been designed to protect individuals in this sensitive area.

The Registry is physically housed in Education and the coordinator hired by Health. The Registry is under the direction of a Health, Social Services, Education (Interagency) Management Board, chaired by Frederick I. White, Ed. D. The Registry Director is Richard F. Gaufin, Ph.D.

Organizational Structure of the URH

People of Utah through
Statutes

Joint Interagency Coordinating Committee

Interagency Management Board

IMISH Registry Coordinator

Ad Hoc Committee Appointed by the Management Board
With Approval of the JICC

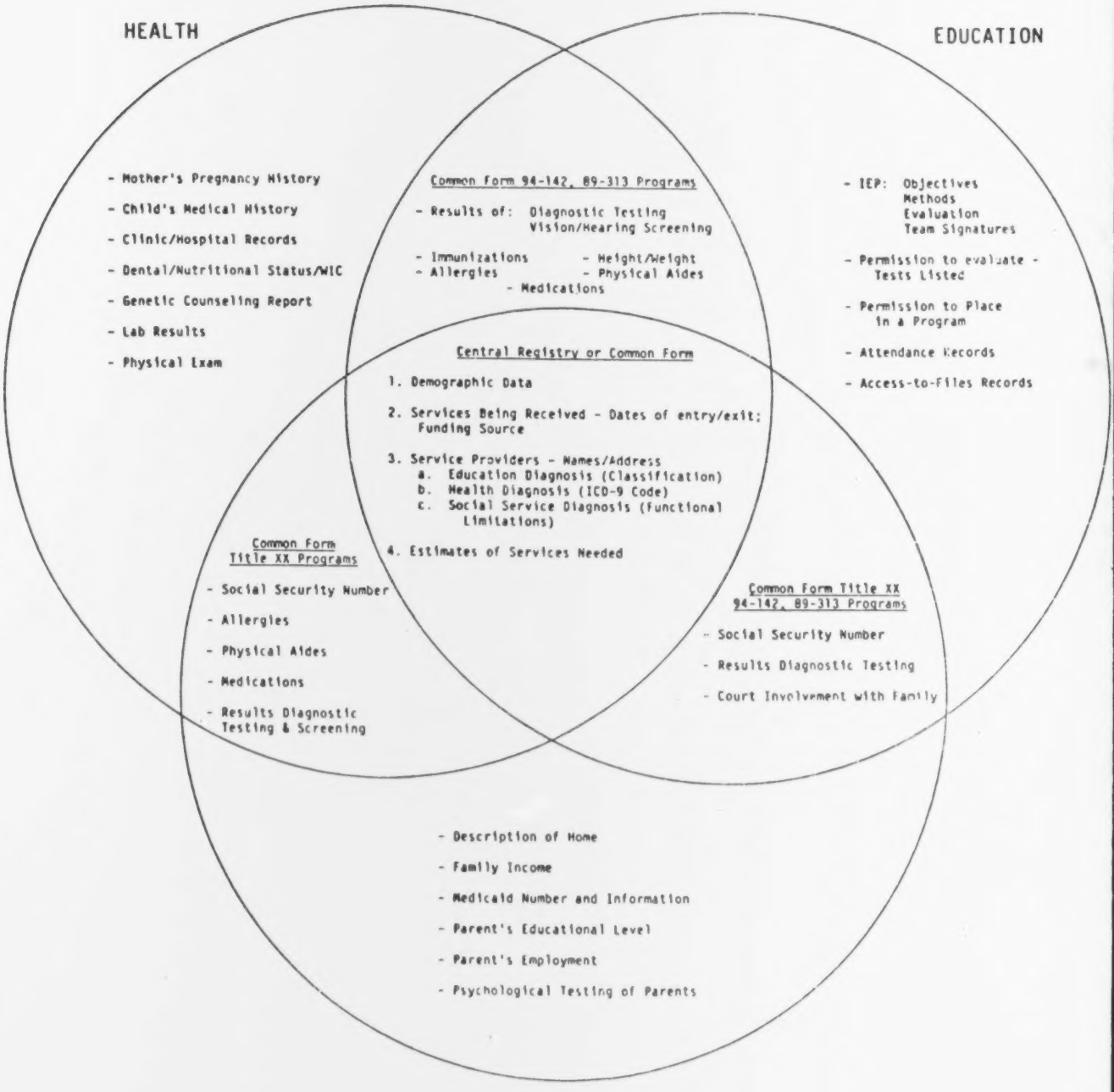
Timetable

Three documents about the Utah Registry for Handicapped Persons are in near-final form:

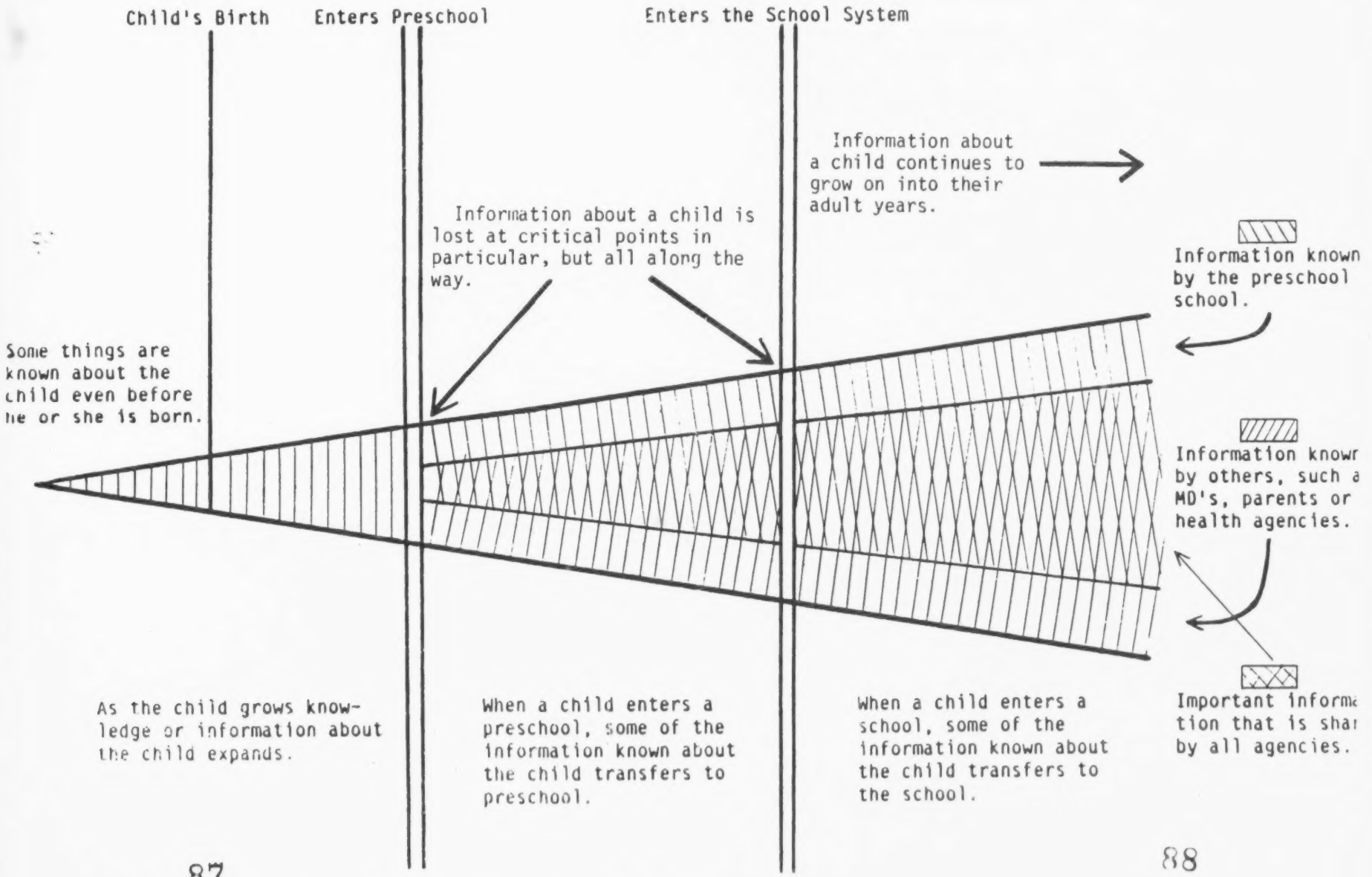
1. **System Documentation Manual.** This is a technical document that describes the computer program and its operation.
2. Up-date to **Policies, Organization, and Administration Manual.**
3. **Application and Procedures Manual.** This is a user and informational manual derived from the first two documents. It will be of broad interest, and will be available for distribution by September, 1985.

A prototype of the Utah Registry for Handicapped Persons will begin operation by the end of July 1985. It will be revised and fully implemented by October 1, 1985.

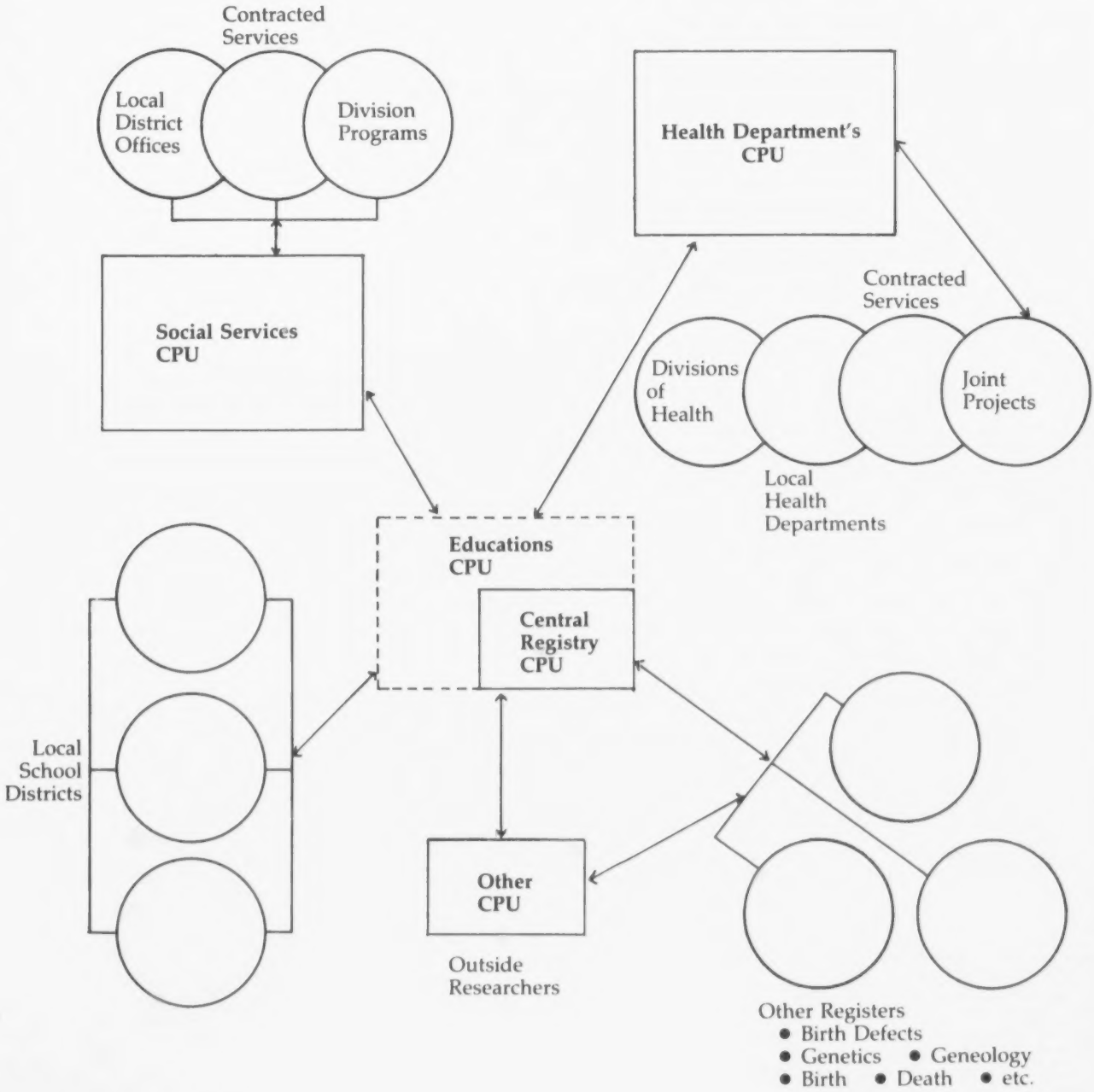
INFORMATION COLLECTED BY HEALTH, EDUCATION AND SOCIAL SERVICES



INFORMATION GROWTH ABOUT A CHILD


Child's Birth
Enters Preschool
Enters the School System
Information about a child continues to grow on into their adult years.
Information about a child is lost at critical points in particular, but all along the way.
Information known by the preschool school.
Some things are known about the child even before he or she is born.
Information known by others, such a MD's, parents or health agencies.
Important informa tion that is sha by all agencies.
As the child grows knowledge or information about the child expands.
When a child enters a preschool, some of the information known about the child transfers to preschool.
When a child enters a school, some of the information known about the child transfers to the school.

The Utah Registry for the Handicapped
or
The Interagency Management Information System for the Handicapped (IMISH)



Washington

WASHINGTON STATE HIGH PRIORITY INFANT TRACKING PROJECT

Beginning in October, 1982 the State Maternal and Child Health Services, in coordination with the University of Washington implemented the "High Priority Infant Tracking Program" as a pilot project in Whatcom County, Washington. This program was designed to meet the following objectives:

1. To assist parents in securing or maintaining ongoing health supervision and developmental surveillance for their child through the first three years of life.
2. To facilitate the early identification of infants requiring further evaluation, intervention, and other support services.
3. To collect systematic data regarding state and local patterns of child health supervision, utilization of available resources, and incidence of disabilities among high priority infants, in order to improve health and educational services.

The High Priority Infant Tracking Program includes identifying high priority infants according to the "high priority" indicators listed on the identification form (e.g., low birthweight, seizures, birth defects, social concerns, etc). The infants are identified by the discharging hospital caring for infants with Whatcom County addresses. These hospitals include St. Joseph's Hospital, Bellingham; Children's Orthopedic Hospital and Medical Center, Seattle; and University Hospital, Seattle. After parental consent is obtained, the child is enrolled into the tracking program. The Identification Form is sent to the Health Department, and the Health Department sends out the Tracking Form at three months, six months, twelve months, 18 months, 24 months and 36 months. The Tracking Form asks the health care provider to indicate the status of the child's health and development, and whether or not other community services are being utilized by the family. The tracking form also asks whether or not the child is continuing to receive ongoing health surveillance. If the child is not receiving care, the Health Department attempts to contact the family and facilitate re-entry into the health care system.

This program has now completed the first two years of the pilot project. More than 150 infants have been identified as high priority and successfully enrolled into the tracking system. Eighty-five to 90 percent have been successfully maintained within the health care system up to 12 months of age. The later tracking periods have not yet been completed, and thus not fully evaluated.

Because of the need to fully evaluate the effectiveness of this project before state-wide implementation, a second matched county has been added to the pilot project. Infants residing in Thurston County have begun to be identified as high priority and enrolled into the tracking project, and are at various stages of the tracking system. Only two infants have questionable follow-up health care.

Data analysis of the Identification Forms and the Tracking Forms is now being done to evaluate the project's effectiveness, assess the appropriateness of the identifying criteria for predicting future health and developmental problems, and evaluate the use of community services within a community. Interesting findings include the success rate of maintaining high priority infants within the health care system (85-95 percent successful), the significant relationship between birth defects identified at birth with future health and/or developmental problems, and the significant relationship between health problems at the different tracking stages up to twelve months and developmental problems at the same or future tracking periods.

If the success of this program continues at its' present rate, the Washington State High Priority Infant Tracking Project will be implemented state-wide.

WASHINGTON STATE

HIGH PRIORITY INFANT TRACKING PROGRAM

Information for Parents

DEPARTMENT OF SOCIAL & HEALTH SERVICES

A Program of
The Washington State
Office of Community Health Services
Maternal & Child Health Section
Department of Social and Health Services
Mail Stop LC-12A
Olympia, Washington 98504

22-283 (10/82)

DEAR PARENT

Your new baby has been identified as a candidate for the Washington State High Priority Infant Tracking Program. Please take a few minutes to read about the program.

WHAT IS THE HIGH PRIORITY INFANT TRACKING PROGRAM?

The program was developed by physicians, nurses, State and local health departments and hospitals in Washington with two major goals in mind:

1. To assist parents to secure or maintain ongoing child health supervision and developmental surveillance through the first 3 years of life.
2. To help in planning for the health and educational needs of the children of our state.

HOW WAS MY BABY CHOSEN?

The High Priority Infant Tracking Program has selected a list of conditions which, when present at birth, place a baby so identified in a "high priority" category. Your baby has been identified as having one of these conditions. This is done to assist parents in obtaining and maintaining ongoing health and developmental care during the first few years of life.

WHAT IS THE CONDITION MY BABY HAS?

There are a large number of conditions such as low birth weight, heart problems, which indicate a need for close follow-up of the health of some infants. We have asked your baby's attending physician to explain which condition resulted in your baby being selected. Furthermore, the doctor will be able to discuss the significance of the condition for your baby, both now and in the future.

HOW DOES THE PROGRAM WORK?

After you sign the permission form, the following information will be sent to your local health department:

1. your name and your baby's name.
2. your address and phone number.
3. the length of your pregnancy and your baby's birth weight.
4. the condition or conditions identifying your baby as a "high priority infant".
5. the name of the doctor or health facility who will be caring for your baby after you leave the hospital.

When your baby is about 3, 6, 12, 24 and 36 months old, personnel in your local health department will contact your baby's doctor or health facility to find out whether your baby is still being seen there regularly and to ask how he/she is developing. If your baby is not being cared for by the doctor or health care facility listed, a public health nurse will contact you to ask to whom you are taking your baby. If you are having difficulty obtaining routine well baby care, the nurse contacting you will be happy to help you obtain such care.

YOUR CHILD WILL BE KNOWN BY NAME TO YOUR LOCAL HEALTH DEPARTMENT AND YOUR PHYSICIAN **ONLY**. Only summary statistics on all infants will be collected by the state health agency.

DO I HAVE TO GIVE MY PERMISSION?

The program is entirely voluntary and unless you sign the permission form, your baby will not be enrolled in the program. The care your infant receives in the hospital

will in no way be affected by your refusal or acceptance of the High Priority Infant Tracking Program.

CAN I WITHDRAW FROM PARTICIPATING LATER?

Yes. If you decide to withdraw your name and your baby's name from participation, you may do so at any time by notifying your physician or contacting your local health department.

IF I HAVE FURTHER QUESTIONS ABOUT THE PROGRAM, HOW CAN THEY BE ANSWERED?

Your baby's doctor and your local health department will be able to answer any questions you have about the program. Contact your baby's doctor or the nursing service at your local health department

(_____

_____)

for further information.

We hope you will join us in this project with the overall goal of improving health and development of young children throughout the state.

Thank you,

The Washington State High Priority Infant Tracking Program.

Discrimination is prohibited in all programs and activities; no one shall be excluded on the basis of race, color, religion, creed, national origin, sex, age or handicap.

HIGH PRIORITY INFANT IDENTIFICATION FORM **OF WASHINGTON STATE** CASE NUMBER _____

PATIENT DATA

CHILD'S NAME: _____
(last) (first) (middle)

DATE OF BIRTH: _____ GESTATION (weeks): _____ ( ) Male ( ) Female

Infant born in this hospital: ( ) Yes ( ) No. If no, hospital of birth: _____

MOTHER'S NAME: _____
(last) (first) (middle)

FATHER'S NAME: _____
(last) (first) (middle)

GUARDIAN, if any: _____
(last) (first) (relationship)

ADDRESS: _____ TELEPHONE: _____
(street or route no.) (town)

_____
(county) (zip)

Name of persons other than parents who will know where child can be located:

1. _____
(name) (address) (telephone no.)

2. _____
(name) (address) (telephone no.)

HIGH PRIORITY INDICATORS (CHECK ALL THAT APPLY)

( ) Birth weight ≤5 lbs. 8 oz. (≤2500 gms.) BIRTH WEIGHT: _____ gms.
( ) Birth weight ≤10th %tile for gestational age (SGA) ____ lb. ____ oz.
( ) Head Circumference (OFC) ≤10th %tile or ≥90th %tile for gestational age OFC: ____ in./cms.
( ) Apgar score less than 4 at 5 minutes APGAR _____
( ) Intracranial hemorrhage
( ) Seizures
( ) Clinical impression of neurological abnormality DESCRIBE: _____
( ) Acquired CNS infection (e.g., meningitis) DESCRIBE: _____
( ) Hyperbilirubinemia (≥20 mg%) mg%: _____
( ) Suspected/confirmed hearing impairment
( ) Suspected/confirmed visual impairment
( ) Major birth defect or syndrome DESCRIBE: _____
( ) Congenital fetal infection: ( ) toxoplasmosis ( ) rubella ( ) herpes ( ) cytomegalic virus ( ) syphilis
( ) Confirmed congenital hypothyroidism
( ) Confirmed PKU
( ) Mother 15 years of age or under AGE ____ yrs.
( ) Significant environmental, social, or parenting risk DESCRIBE: _____
( ) Other problems: _____

FORM COMPLETED BY: _____ DATE: _____

I have reviewed the above information and believe it to be correct.

_____ DATE: _____
(Attending Physician Signature)

PARENT'S PERMISSION

I have had the "High Priority Infant Tracking Program" explained to me orally and in writing and agree to having my baby enrolled. I understand that enrolling my infant in this program requires sending certain personal and medical information as indicated above to my child's health care provider and to the local health department where my child resides presently or in the future. I understand I can withdraw my child from this program at any time. My child's health provider is:

_____
(name of health provider)

_____
(address) (town) (state) (zip)

_____ _____
(Witness' Signature) (Parent's Signature)

_____ _____
(Date) (Date)

( ) Refused tracking system: _____

TIME RECORD FOR THIS PATIENT

HOSPITAL STAFF

TIME SPENT ON HPIT: Please check appropriate time spent in each activity.

IDENTIFICATION (eg. identifying infant; preparing forms and charts, etc.)
( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.
( ) 30-35 min. ( ) Other specify in minutes: _____

PARENT CONTACT (eg. obtaining consent; explaining program, etc.)
( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.
( ) 30-35 min. ( ) Other specify in minutes: _____

HEALTH DISCIPLINE CONTACTS (eg. communication with other staff relative to HPIT activities)
( ) None ( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.
( ) 30-35 min. ( ) Other specify in minutes: _____

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FORM SENT TO: _____ CASE NUMBER _____

HIGH PRIORITY INFANT TRACKING FORM OF WASHINGTON STATE

PATIENT DATA

CHILD'S NAME: _____ DATE OF BIRTH: _____

PARENT'S NAME: _____ TELEPHONE: _____

ADDRESS: _____

(street or route number) (town) (county) (zip)

If different from above, please correct: _____

RETURN FORM TO

AGENCY: _____ ATTENTION: _____
(person requesting information)

ADDRESS: _____ TELEPHONE: _____

Check TRACKING CONTACT: ( ) 3-4 mos. ( ) 6-7 mos. ( ) 12 mos. ( ) 24 mos. ( ) 36 mos.

TRACKING DATA

Is this child still receiving health care from you? ( ) Yes ( ) No

If no, indicate reason: ( ) Don't know ( ) Cannot locate ( ) Deceased

( ) Moved to: _____ (state or county)

( ) Referred to another physician: _____

Address: _____

( ) Other: _____

Please indicate:

I. HEALTH STATUS: ( ) Normal ( ) Other. If other, check **MAJOR** problems and specify as necessary below.

( ) A. CNS. ( ) Cerebral Palsy ( ) Seizures ( ) Hydrocephalus

( ) Structural defects, specify: _____

( ) Other: _____

( ) B. Pulmonary, specify: _____

( ) C. Cardiac, specify: _____

( ) D. Renal, specify: _____

( ) E. GI, specify: _____

( ) F. Growth Disorders: ( ) Failure to thrive

( ) Head Circumference (≤3rd %tile or ≥97th %tile)

( ) G. Malformation or syndromes, specify: _____

( ) H. Sociomedical: ( ) Child abuse/neglect ( ) Other, specify: _____

( ) I. Other, specify: _____

II. BEHAVORIAL/SENSORY DEVELOPMENT

A. Developmental Milestones — considering age (corrected for prematurity if any)

1. Personal-social: ( ) Normal ( ) Questionable ( ) Abnormal ( ) in treatment
2. Fine motor: ( ) Normal ( ) Questionable ( ) Abnormal ( ) in treatment
3. Gross motor: ( ) Normal ( ) Questionable ( ) Abnormal ( ) in treatment
4. Language: ( ) Normal ( ) Questionable ( ) Abnormal ( ) in treatment
5. Mental: ( ) Normal ( ) Questionable ( ) Abnormal ( ) in treatment

B. Vision: ( ) Normal ( ) Abnormal, specify: _____

C. Hearing: ( ) Normal ( ) Abnormal, specify: _____

D. Other, specify: _____

III. INTERVENTION SERVICES

A. With respect to the problems mentioned above, has the child and family received services from other community agencies during the past year?

( ) No ( ) Yes. If yes, specify type: _____

B. If no, why is the child not receiving these services? ( ) managing problems myself

( ) family refused ( ) appropriate services not available in community

TIME RECORD

FOR PRIMARY HEALTH CARE PROVIDER ONLY: Please check appropriate box indicating time spent in completing form.

( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min. ( ) 30-35 min.

( ) Other, please specify in minutes _____

CASE CLOSURE

FOR PHN ONLY:

Date of closure: _____ Reason: Moved out of ( ) state or ( ) county

( ) Parental permission withdrawn

( ) Cannot locate ( ) Deceased

TIME RECORD FOR THIS PATIENT

Time spent on HPIT: Please check appropriate time spent in activity

ADMINISTRATION (eg. developing file, sending tracking form, etc.)

( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min. ( ) 30-35 min.

( ) Other, please specify in minutes _____

PARENT CONTACT (eg. activities related to tracking lost infant; follow-up, etc.)

( ) none ( ) 1-20 min. ( ) 31-60 min. ( ) 61-120 min. ( ) 2-3 hrs. ( ) 3-4 hrs.

( ) Other, please specify in hours _____

PRIMARY HEALTH CARE PROVIDER CONTACT (eg. communication relative to HPIT activities)

( ) none ( ) 1-10 min. ( ) 11-20 min. ( ) 21-31 min. ( ) 32-42 min. ( ) 43-53 min.

( ) 54-64 min. ( ) Other, please specify in hrs. _____

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